

June 2011

Year of Care

Report of findings from the pilot programme



Preface

Diabetes is an exemplar for many long term conditions (LTCs) which are increasing in prevalence year on year. It challenges the NHS to ensure that everyone receives the highest standards of care no matter where, when or by whom that care is delivered. Services need to be seamless and focus on the whole needs of the person, working across financial and organisational boundaries including primary, secondary and non-traditional third sector providers.

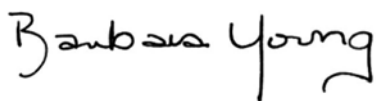
Achieving best outcomes is about the delivery of safe, effective and efficient diabetes care. It is also dependent on changing how the NHS relates to those accessing healthcare services to provide greater personalisation and support. People with LTCs, such as diabetes, need the knowledge, skills and confidence to manage their own health to the degree they feel comfortable with. This culture change needs both people with diabetes and healthcare professionals to learn new ways of working together to prevent the personally devastating and costly complications of heart disease, amputations, kidney disease and blindness.

The diabetes Year of Care Programme has sought to address these issues. This report outlines the very real achievements of a three year pilot programme working across three diverse health communities (North of Tyne, Calderdale and Kirklees and Tower Hamlets). The local teams have been able to demonstrate how to deliver personal care planning and better support for self management for people with diabetes in their areas and at the same time show how this can support better integration of local services. This includes new partners in the third sector and other organisations who can provide therapeutic, lifestyle and social support in peoples' own communities.

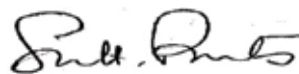
These joint approaches lead to better experience for people with diabetes and healthcare professionals alike. People report feeling more in control and many are beginning to be able to address some of the lifestyle issues they may have been struggling with for years. Some practices have been able to make real improvements in productivity by altering how they share and organise tasks. Overall this increase in quality of care was achieved at no increased cost.

None of this could have been achieved without the hard work of the pilot sites who committed personal and local resources well beyond what was expected, because they found working in this new way was better for everyone. It is a process of building relationships based on partnership working recognised by the National Institute of Health and Clinical Excellence in the Diabetes Quality Standard for care planning and the Royal College of General Practitioners who have adopted care planning as a professional standard for GPs. We believe that this will impact positively on people with diabetes and those with other LTCs. We hope that care planning will become the norm for these groups.

This will only come about if policy makers, commissioners, healthcare professionals and people with diabetes work together to make it happen. We recommend this report, the accompanying case studies, the headline messages and practical experience to all those who wish to join us in this endeavour.



Barbara Young
Chief Executive, Diabetes UK



Dr Sue Roberts
Clinical Lead, Year of Care Programme Board

Making it mainstream

Year of Care Programme report: 2011

This is the final report of the Year of Care (YOC) pilot project. It describes the background, aims and objectives, parallel evaluations, the way the programme was delivered and its impact.

Case studies on each of the pilot sites are being published simultaneously and these documents complement each other. Between them they provide the learning to support wider implementation of the YOC approach to care planning and the lessons for commissioning for long term conditions (LTCs).

This work will be of interest to policy makers, those with broad interests in commissioning and service delivery of personalised care for those with LTCs, and anyone contemplating introducing and embedding a programme of cultural change across the NHS.

“Before, things seemed to get forced on you... whereas this way I prefer to discuss it myself... there’s more of a choice now, it’s my choice rather than someone else’s choice, that’s why I like it.”

Person with diabetes, reporting on their experience of the YOC approach to care planning

“If I were a patient I would want to have a care planning system in place. I think it respects people more as individuals. It gives people more rights.”

Practice nurse, involved in care planning

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Executive summary

The Year of Care (YOC) Programme

'Working together for better healthcare and better self care'

Introduction

The YOC Programme has demonstrated how to deliver personalised care in routine practice for people with long term conditions (LTCs), using diabetes as an exemplar. The approach puts people with LTCs firmly in the driving seat of their care and supports them to self manage. It transforms the diabetes annual review into a constructive and meaningful dialogue between the healthcare professional and the person with diabetes. The YOC Programme has two components:

- *Firstly* it enhances the routine biomedical surveillance and 'QOF review' with a collaborative consultation, based on shared decision making and self management support, via care planning
- *and then* ensures there is a choice of local services people need to support the actions they want to take to improve their health, wellbeing and health outcomes, available through commissioning.

YOC provides practical evidence and support to implement the White Paper *Equity and Excellence: Liberating the NHS proposals for personalised care 'no decision about me without me'* and locally-driven flexible commissioning for people with LTCs and the QIPP agenda. Care planning is included in the NICE Quality Standard for diabetes. YOC has worked closely with the Royal College of General Practitioners (RCGP) who are developing professional standards for care planning to be incorporated into training.

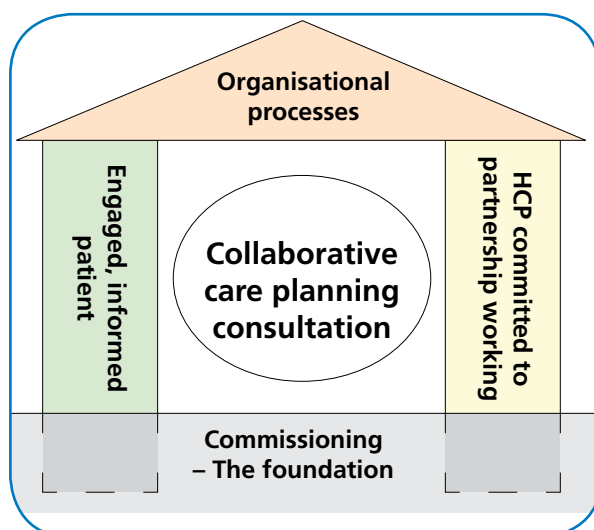
Care planning

"Care planning has made me look at patients differently. I focus less on the disease and take a more holistic perspective."

Practice nurse

"Each time I get a greater understanding of my condition and understand more about how I can go about maintaining and improving it."

Person with diabetes



Care planning is a process which offers people active involvement in deciding, agreeing and owning how their diabetes will be managed. It replaces current routine care.

The YOC Programme found that effective care planning consultations rely on three elements working together in the local healthcare system: an engaged, empowered patient working with healthcare professionals (HCPs) committed to a partnership approach, supported by appropriate/robust organisational systems. This is illustrated by the YOC Care Planning House Model (left). This model emphasises the importance and interdependence of each element – if one is weak or missing the structure is not fit for purpose.

YOC worked with three pilot PCTs: Tower Hamlets (TH), Calderdale and Kirklees (CK) and North of Tyne (NOT) – North Tyneside (NT) and West Northumberland (WN) – and 12 other health communities to test transferability.

Key achievements over three years

- Care planning has been adopted as the norm in a majority of practices across the pilot communities: TH = 97%, Kirklees = 83%, NT = 79% and WN = 73%.
- 76% of people with Type 2 diabetes on practice registers have had at least one care planning consultation.
- Care planning works across diverse populations thus addressing inequalities.
- The National Training and Support Programme has trained 1,000 HCPs and quality assured 40+ local trainers.

Care planning: the benefits

- People with diabetes report improved experience of care and real changes in self care behaviour.
- Professionals report improved knowledge and skills, and greater job satisfaction.
- Practices report better organisation and team work.
- Productivity is improved: care planning is cost neutral at practice level: there are savings for some.
- Care planning takes time to embed: changes in clinical indicators across populations may be seen after two or three care planning cycles.

Key lessons for wider implementation

- Culture and systems must change to support a new way of working.
- Successful implementation across a health community involves a partnership between grass roots ownership, local innovation and tailoring, and strong clinical (usually primary care) leadership – ‘right from the top, right from the start, right the way through’.
- This must be supported by local flexible commissioning, practice facilitation and tailored training – ‘making it easy to do the right thing.’
- Staff must be clear about their roles, and where care planning fits in the local pathway/model of care.
- There are extra costs at start up for communities with poor health literacy.
- Care planning is being tested in other long term conditions (LTCs).

Commissioning

YOC seeks to ensure that appropriate local services are commissioned to support the choices people make with their HCPs during care planning to support self management to achieve and maintain good health and wellbeing. The YOC IT project improves capture and transfer of care planning information. YOC have also published *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Providers to Support the Self Management of People with Long Term Conditions*, which describes the barriers and suggests solutions.

Introducing care planning and better support for self management at the centre of care for people with LTCs stimulated service redesign, new approaches to commissioning and whole system change, leading to better integration of services.

Examples including real reduction in costs are outlined in YOC information sheet *Commissioning for Diabetes and other Long Term Conditions: Spring 2011*.



YOC makes available

- A tested National Training and Support Programme to support delivery of care planning in primary and specialist care. This includes quality-assured 'training the trainers', facilitation of delivery, and links with unique IT templates to record patient goals, action plans and service needs.
- With thanks to the Royal College of General Practitioners (RCGP); their report *Care Planning – Improving the Lives of People with Long Term Conditions*; a practical guide for clinical teams on putting the YOC care planning model into practice.

“It’s absolutely 100% better for me and the patients.”

GP

Introduction

The pilot phase of the Year of Care (YOC) Programme has come to an end. In just over three years, working with three diverse communities (NHS Calderdale & Kirklees, NHS North of Tyne and NHS Tower Hamlets), YOC has demonstrated how to introduce and embed personal care planning into routine care for people with long term conditions (LTCs), using diabetes as an exemplar.

The three sites used their learning from YOC to reframe their commissioning agendas for LTCs, using the practical delivery of care planning to drive essential changes at organisational as well as at individual level. Their thinking moved on from the 'task' of introducing patient-centred care into health service institutions as they currently operate, to one in which the components were completely realigned. This was not just with the point of view of people with diabetes in mind, but also based on a delivery mechanism in which increasing the individuals' control over decisions about their management and better supported self management are the key outcomes.

Whilst the immense cultural changes involved in this take time, the care planning model and the linked training and support programme introduce an intervention that changes systems right from the start, providing a platform from which both people with LTCs, such as diabetes, and practitioners can learn to improve and develop as they work together day-by-day, co-producing a health service fit for the needs of the 21st century.

YOC addresses the issues at the heart of the current challenges facing the National Health Service. Changing demographics due to aging, increasing prevalence of diabetes¹ other LTCs and more co-morbidity, means the NHS cannot survive economically without fundamental change. The second, cultural challenge, in which individuals demand greater control over their own health and the healthcare decisions made about them, can paradoxically provide at least part of the solution; when it is recognised that effective self management can add economic value to the service, as well as addressing the individual's desire for greater control and involvement.

These challenges have been well described and are well understood. Up to now it has not been possible to demonstrate effective practical solutions that are able to deliver change *to* the current system, *from within* the current system.

The YOC Programme can demonstrate significant change at personal, practice and local health system levels, describing the steps through which this has been achieved so that this can be replicated by others. The programme would like to ensure that care planning and its individual and cultural benefits become 'mainstream'. Working with and through other national and local initiatives addressing similar issues is essential in refocusing the institutions of the NHS on the practical delivery of a new sort of relationship with those who use the service, building from the grassroots.

Care planning provides the framework for the national personalisation agenda and the policy imperative '*no decision about me without me*'. YOC shows how this can delivered in practice. The Inquiry into the Quality of General Practice in England³ recommended that primary care needs to raise its game in terms of its organisation, improvement processes and more equal partnership with patients, in which they are supported to become active participants in the care and services they receive. YOC practices have been able to start to do this. A wide range of institutions including the Royal College of General Practitioners (RCGP) and Royal College of Physicians (RCP) are promoting greater integration of care, and the YOC pilot sites have provided a commissioning model to support this.

1 Diabetes UK. (2010). *Diabetes in the UK*. (Online) Available from www.diabetes.org.uk/Documents/Reports

2 Department of Health. (2010). *Equity and Excellence: Liberating the NHS*

3 King's Fund. (2011). *Improving the Quality of Care in General Practice. Report of an Independent Inquiry Commissioned by The King's Fund*

There is a strong international evidence base for what works to deliver better outcomes for people with LTCs, brought together in the Chronic Care Model⁴ and its UK version⁵. The key message is that better outcomes are achieved by prepared practice teams working in partnership with informed activated patients; and that support for self management (SSM) is the most significant ingredient. Care planning as developed by YOC and described in this report, is simply a structured delivery mechanism for this, which works in practice.

This report emphasises some critical aspects for delivery. Changes in attitudes, skills and service infrastructure must be introduced together. Changes in attitudes and skills without change in the infrastructure to support them, leads to demoralisation; and changes in systems without changes in attitudes are ineffective in delivering change in practice. When both were in place healthcare professionals found this a more satisfying way of working.

Consistent leadership and clarity of purpose, *right from the top, right from the start and right the way through* was critical. This needed to include GPs and those with the authority to influence both commissioning and delivery at the grass roots. Care planning needed to be a part of the local commissioning agenda and be clearly identified in local models and pathways of care. Commissioning for wider patient and public engagement was important, especially in disadvantaged communities. Finally practice teams needed facilitative support to set up, embed and engage in self reflection and improvement.

The importance of dovetailing all these components so that grassroots staff received consistent messages, and that these were represented in the support, tailored resources provided including IT, and metrics cannot be over-emphasised. The programme brought these together in a National Training and Support Programme. This provides set up advice for local steering groups, basic modules for clinicians, awareness modules for other practice staff, and those working in the wider community such as district nurses; and a quality-assured 'Training the Trainers' package to enable services to develop locally based trainers to help roll out the programme across their local communities. To date, 1000 practitioners and 40 (soon to be 60) trainers have taken part in the programme in 15 health communities, and regularly report changes in attitudes, behaviours and clinical systems. *"I am no longer a cynic"* is a typical comment.

The YOC Programme has also had wider influence. The RCGP has produced a guide to care planning based on the YOC approach, *Care Planning – Improving the Lives of People with Long Term Conditions*⁶. This provides a detailed guide for clinicians on how to introduce and evaluate care planning in their practices. The College have identified funds to appoint a clinical lead to take this work forward with a network of interested practitioners, and develop professional standards for care planning to be incorporated into training.

The National Institute for Health and Clinical Excellence (NICE) has included care planning as one of 13 National Quality Standard statements for diabetes⁷, citing the YOC approach. It is hoped that these two national initiatives will help care planning become embedded in both primary care and cross the whole diabetes community.

The YOC Programme was also charged with ensuring the local services that people choose during the care planning consultation (micro commissioning), as needed to support them, are identified and then made available through (macro) commissioning. It addressed the recording and reporting of these choices by working with software developers and system suppliers to develop IT solutions. These are only now becoming available as the project ends its feasibility stage.

Both the *need for* a much wider range of non-traditional community services to support self management and increase individual choice, and the *lack of* any systematic approach to develop or commission these from third sector and other organisations was identified as widespread across England. Using innovation funds from NHS North East, the North of Tyne YOC pilot carried out a specific piece of work to address this, resulting in a

4 Wagner, EH, Austin BT, Von Korff, M. (1996) *Organising Care for Patients with Chronic Illness*. The Millbank Quarterly; 74(4)

5 Department of Health. (2005). *Supporting People with LTCs*. (Online) Available from www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122574.pdf

6 Royal College of General Practitioners. (2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk

7 National Institute for Health and Clinical Excellence (NICE). (2011). *Diabetes in Adults Quality Standard*. (Online) Available from www.nice.org.uk/guidance/qualitystandards/diabetesinadults/diabetesinadultsqualitystandard.jsp

publication *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self Management of People with Long Term Conditions*.⁸

The YOC Programme has successfully developed the three components of the YOC model, care planning, better community support services and the IT to link them. However, no pilot site was able to link them all together during the timescale of the pilot phase. This work is now being taken forward by three clinical commissioning groups across North of Tyne, funded by the Northeast HIEC (Health Innovation and Education Cluster) programme. The aim is to test the links over one year before further spread.

Thus, while the YOC pilot phase has ended, the YOC Programme will go on. Plans are being developed to set up a participant community of practice to enable the rapidly increasing experience of delivery to be shared across sites, and for the increasing local expertise to inform further development of the Training and Support Programme.

Using the report

This report has been written with two purposes in mind. Firstly, the aim is to summarise the key learning from the project so that it is available for others to consider and use. Secondly, it is to act as the formal report of the activities and findings of the pilot programme.

There are three linked case studies one from each YOC site, which describe in more detail how the project was set up and implemented over the three-year period. These include a wealth of information about the experiences of these very different health communities. Each describes their journey and gives advice for others contemplating embarking on this road themselves.

We are grateful to the RCGP for allowing us formally to signpost readers to their report, *Care Planning – Improving the Live of People with Long Term Conditions*⁹ as the definitive 'how to do it' guide for primary care and other clinical teams. It takes the reader on a walk round the Care Planning House Model and discusses evaluation in detail.

This report is divided into two main sections on care planning and commissioning respectively, with a final section on the issues of introducing a complex intervention such as care planning into a complex environment such as the NHS; and a summary of the achievements against the objectives of the project.

Each chapter starts with a brief description of its content and the relevant key messages are highlighted. We suggest that readers may want to move through these from chapter to chapter before delving into the detail and discussion within the chapters that interest them. Information that is particularly 'technical' is included in the appendices. These also include information sheets about key aspects of the work that can be printed off or photocopied as summaries.

We hope you find some or all of this relevant to your own practice. We would like to thank the Programme's partners, NHS Diabetes, Diabetes UK, The Department of Health, and The Health Foundation who have all supported the project financially in some way, and even more so in the help and advice they have given us on the Partnership and Programme Boards. We would especially like to thank our pilot sites for the enormous amount of work they put into realising the programme's aspirations to improve the experiences of people with diabetes in their care, and for providing the learning that has been so valuable to the programme. Our confidence about the findings we are presenting is in part due also to the work we have done and are continuing to do with 12 non-YOC pilot early implementer communities, with whom we have been able to validate or challenge many of our emerging assumptions. We would like to thank them too and look forward to working with them further in the future.

8 Year of Care.(2011). *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self Management of People with Long Term Conditions*. (Online) Available from www.diabetes.nhs.uk/year_of_care/commissioning/thanks_for_the_petunias_a_guide_to_developing_and_commissioning_nontraditional_providers

9 Royal College of General Practitioners. (2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk

Chapter 1: Policy context and key achievements

This chapter gives the policy context and headline learning from the Year of Care (YOC) Programme.

Key points

- The YOC Programme has demonstrated how to deliver personalised care planning in routine practice for people with long term conditions (LTCs) using diabetes as an exemplar.
- Care planning provides a framework to support the policy imperative of ‘no decision about me without me’ prioritised within the new white paper *Equity and Excellence: Liberating the NHS (2010)*¹⁰ and is the gateway for informing choice through personalisation.
- The YOC approach has provided the practical base from which the Royal College of General Practitioners (RCGP) plan to produce professional standards for care planning, and on which the NICE National Quality Standard¹¹ for care planning in diabetes is based.
- YOC has developed a guide to commissioning for non-traditional services to support self management and a new commissioning model for LTCs.
- YOC proposes that when considering delivery... ‘it’s not only what you do, it’s how you do it’.

Background, policy context and learning

A commitment to ‘patient centred care’ and ‘personalisation’ has been a key plank of national policy for a decade.

“The health and social care system must be shaped around the needs of the patient, not the other way round. Step by step over the next ten years the NHS must be redesigned to be patient centred – to offer a personalised service... by 2010 it will be commonplace.”¹²

However patients have reported little improvement in their involvement in decisions about their care and levels of this indicator remain amongst the poorest in countries with developed health systems.¹³ The new White

10 Department of Health. (2010). *Equity and Excellence: Liberating the NHS*

11 National Institute for Health and Clinical Excellence (NICE). (2011). *Diabetes in Adults Quality Standard*. (Online) Available from www.nice.org.uk/guidance/qualitystandards/diabetesinadults/diabetesinadultsqualitystandard.jsp

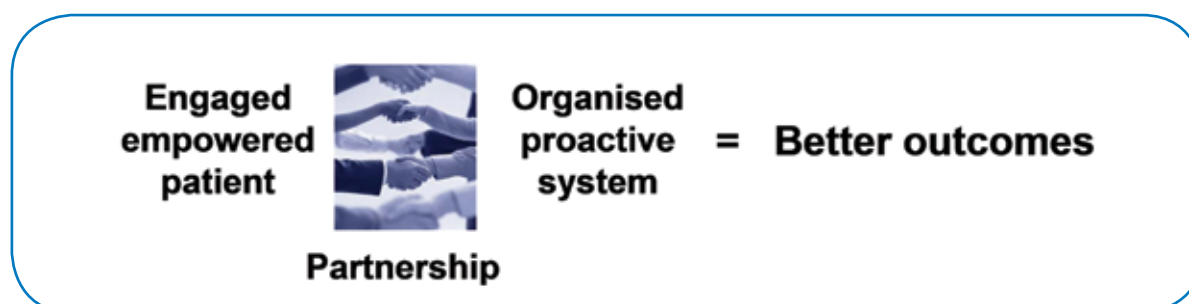
12 Department of Health. (2000). *The NHS Plan: A Plan for Investment, a Plan for Reform*

13 Davis K, Schoen C, Stremikis K. The Commonwealth Fund. (2010). *Mirror, Mirror on the Wall: How the Performance of the U.S. Health Care System Compares Internationally*

Paper *Equity and Excellence: Liberating the NHS*¹⁴ has a clear vision for the NHS and social care system to put the needs of patients and public first, focusing on shared decision making and involving people in their own care and treatment to improve health outcomes.

The large international evidence base, encapsulated in the chronic care model (CCM)¹⁵, suggests that better outcomes **can** be achieved for people with LTCs when there is partnership working between an ‘engaged’, ‘empowered’ or ‘activated’ patient and an organised proactive healthcare system.

Figure 1: The key message adapted from the Chronic Care Model (CCM)



A key component of this model is support for self management (SSM).

“Self care is one of the best examples of how partnerships between the public and health service can work... for every £100 spent on encouraging self care, around £150 worth of benefits can be achieved in return.”¹⁶

The Diabetes National Service Framework Delivery Strategy¹⁷ suggested care planning as an important delivery vehicle for this empowerment and self management agenda.

“A care plan is at the heart of a partnership approach to care and a central part of effective care management. The process of agreeing a care plan offers people active involvement in deciding, agreeing and owning how their diabetes is to be managed.”¹⁷

It emphasised the importance of the process of collaborative consultation leading to the production of the care plan rather than the care plan itself¹⁸, encapsulated in the YOC strap line ‘*it’s a verb and not a noun*’.

During the last five years, care planning has gradually come to be seen as a central component of the health policy in England for everyone with an LTC¹⁹, and the gateway to the structured approach outlined in the CCM. It provided the core of the Choice Model²⁰, the gateway to personal health budgets²¹ and a potential access point for telecare and telehealth.²²

“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.

14 Department of Health. (2010). *Equity and Excellence: Liberating the NHS*

15 Wagner, EH, Austin BT, Von Korff M. (1996). *Organising Care for Patients with Chronic Illness*. The Millbank Quarterly 1996; 74(4) 511–44

16 Wanless D. (2002). *Securing Our Future Health: Taking a Long-Term View*. Final Report. HM Treasury. (Online) Available from http://webarchive.nationalarchives.gov.uk + www.hm-treasury.gov.uk/consult_wanless_final.htm

17 Department of Health. (2003). *National Service Framework for Diabetes: Delivery Strategy*

18 NHS Diabetes. (2008). *Partners in Care: A Guide to Implementing a Care Planning Approach to Diabetes Care*

19 Department of Health. (2006). *Our Health, Our Care, Our Say: A New Direction for Community Services*

20 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*

21 Department of Health. (2010). *Equity and Excellence: Liberating the NHS*

22 Department of Health. (2009). *Whole Systems Demonstrators. An Overview of Telecare and Telehealth*

Personal care plans are agreed by the individual and a lead professional.
Over the next two years, every one of the 15 million people with one or more long term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed with a named lead professional from among the team of staff who help manage their care.”²³

Despite the simplicity of the message, care planning is a complex intervention involving both widespread cultural change, as well as changes to everyday processes and practices for the workforce, across large parts of the NHS.

The YOC programme was commissioned in response to the commitment in the White Paper: *Choosing Health: Making Healthy Choices Easier*.

“The independent sector may have a key role in providing effective behaviour change programmes in ways that are more acceptable than traditional NHS care to some groups of patients. We will test this as part of procurement for a ‘year of care’ for diabetic patients.”²⁴

The focus was on delivery, tackling the real issues of delivering tailored and personalised support to people with LTCs, using diabetes as an exemplar. The aim was to provide better support for people with diabetes to self manage more effectively and thus improve quality of life, better health outcomes and reduce use of NHS resources in the short and long term.

The YOC Programme set out to address issues of feasibility, ‘could it be done’ and practicalities ‘how can it done’ in the real world of the NHS. It has successfully provided the practical evidence and support to achieve this. The programme now has a wealth of practical experience to support delivery of the Government’s agenda to ‘achieve health outcomes that are amongst the best in the world... by involving patients fully in their own care, with decisions made in partnership with clinicians rather than by clinicians alone.’²⁵

A tested platform for delivering the personalisation agenda at the heart of current NHS policy ‘no decision about me without me’, with flexible local commissioning now exists. The YOC model not only sounds sensible but can be delivered with a range of benefits to people with diabetes and potentially other with LTCs, and the clinicians who work with them, generating increased productivity for the NHS and its commissioners and providers.

YOC outputs

The experts interviewed as part of the inquiry commonly reported that the Year of Care approach to diabetes management was approaching what best practice should look like.

*The King’s Fund, 2010*²⁶

The programme created a framework which fostered and enabled the system-wide cultural and attitudinal change needed to improve patient involvement in decisions about their care and a national training and support programme to deliver this (Chapter 7).

23 Darzi A. Department of Health. (2008). *High Quality Care for All: NHS Next Stage Review Final Report*.

24 Department of Health. (2004). *Choosing Health: Making Healthy Choices Easier*

25 Department of Health. (2011). *Equity and excellence: Liberating the NHS*

26 The King’s Fund. (2010). *Managing People with Long-Term Conditions*. Research Paper Goodwin et al. An inquiry into the quality of general practice in England

The approach has been recognised to support the Quality, Innovation, Prevention and Productivity Government Programme (QIPP) agenda LTCs work programme for ‘*empowering patients to maximise self management*’.²⁷ The RCGP²⁸ endorses care planning as a professional standard for GPs building on the YOC model. NICE has included care planning as one of 13 statements within the national *Diabetes in Adults Quality Standard* (2011)²⁹ identifying the YOC approach as the vehicle for practical delivery.

The YOC programme also identified the widespread barriers to commissioning services to support self management and adopt healthy lifestyles in the community, and has developed a model and produced a guide to address this (Chapter 13).

It has had unexpected benefits too. Working on the programme led YOC pilot sites to look anew at how they commissioned and designed services for all people with LTCs. This generated new models of commissioning and new ideas for policy development available for testing or implementation, within new evolving commissioning arrangements (Chapter 16).

Key learning for policy is that not only is the model itself successful, the method of introduction and how it is maintained is crucial. The next chapters report on the details of the YOC approach but with particular emphasis on describing the challenges as well as the successes that underline the assertion that it’s not only *what* you do, it’s *how* you do it.

27 Department of Health. (2010). *Quality, Innovation, Innovation and Productivity (QIPP) Workstream: Long term conditions*. (Online) Available from www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/DH_115448

28 Royal College of General Practitioners. (2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk

29 National Institute for Health and Clinical Excellence (NICE). (2011). *Diabetes in Adults Quality Standard*. (Online) Available from www.nice.org.uk/guidance/qualitystandards/diabetesinadults/diabetesinadultsqualitystandard.jsp

Chapter 2: The case for change and Year of Care response

This chapter describes the rationale for and key components of the Year of Care (YOC) approach.

Key points

- Currently the care that people with long term conditions (LTCs) receive does not meet their needs for supporting self management; contact time is used inefficiently; information and education is not prioritised as part of the care process and outcomes are poor.
- YOC translates the extensive evidence of what works to produce better outcomes, into practice to address this.
- The YOC Programme used two mechanisms to achieve this:
 - **firstly** making routine consultations between clinicians and people with long term conditions truly collaborative, through care planning,
 - and **then** ensuring that the local services people identify as needed to support them are recorded and available, through commissioning.
- There are benefits for:
 - people with diabetes
 - clinicians
 - commissioners.

The previous chapter identified support for self management (SSM) as the intervention which is most effective in achieving improved outcomes in people with long term conditions (LTCs).

SSM recognises that people with LTCs are in charge of their own lives and self management of their condition, and are the primary decision makers about the actions they take in relation to the management of their condition.³⁰ The desired outcome, ie someone who is an effective self manager, is a person 'with the knowledge, skills and confidence to manage their own health and healthcare.' The focus moves from the clinician doing things 'to' the person, to one where enabling clinicians support people's confidence and competence to manage the challenges of living with their condition.

There is a great deal of evidence to show that SSM is not as good as it could be for people with diabetes and other LTCs in England and could be improved.

30 Year of Care. (2008). *Getting to Grips with the Year of Care: A Practical Guide*

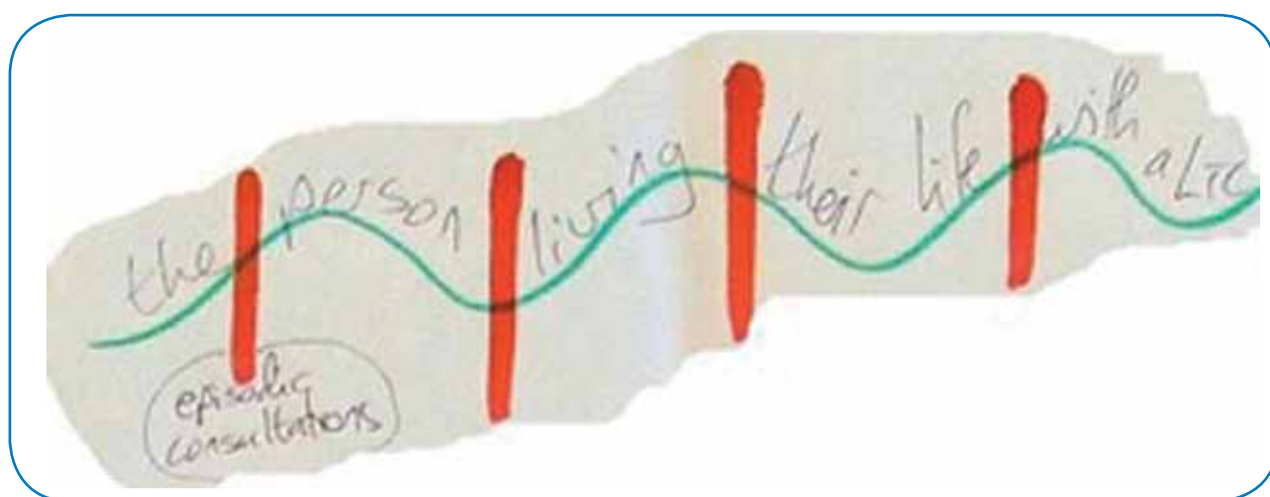
As detailed in the Royal College of General Practitioners (RCGP) care planning document,³¹ there are indications of a lack of engagement by patients in consultations, which include a failure to attend follow-up appointments. Uptake of patient education, even when offered is often poor and less than 15% of people with diabetes have attended.³² As much as 50% of the medication prescribed for LTCs is not taken, or not taken as prescribed.³³ Only 50% of antihypertensive drugs are taken six months after the diagnosis³⁴ and similar 'drop offs' occur with statins.³⁵ All of these issues are likely to be associated with higher admission rates and greater cost to patients and the NHS.

People with LTCs tell us that they want us to do more to support their own self care. However, the evidence also tells us that this is not happening.

According to Mori (2005)³⁶, over 90% of people with LTCs are interested in being more active self carers and over 75% would feel more confident about this if they had help from a HCP or peer; but 30% have never been encouraged by a professional to do so. *The most significant problem is the failure of clinical staff to provide active support for patient engagement.*³⁷

This may be made more difficult by the way in which routine care is provided. At a world café event in 2009, people with LTCs drew this diagram on a table cloth to illustrate what life felt like for them on a day-to-day basis (Figure 2).

Figure 2: A scanned drawing from a world café event to illustrate living with a long term condition and the relationship to contacts with the health service

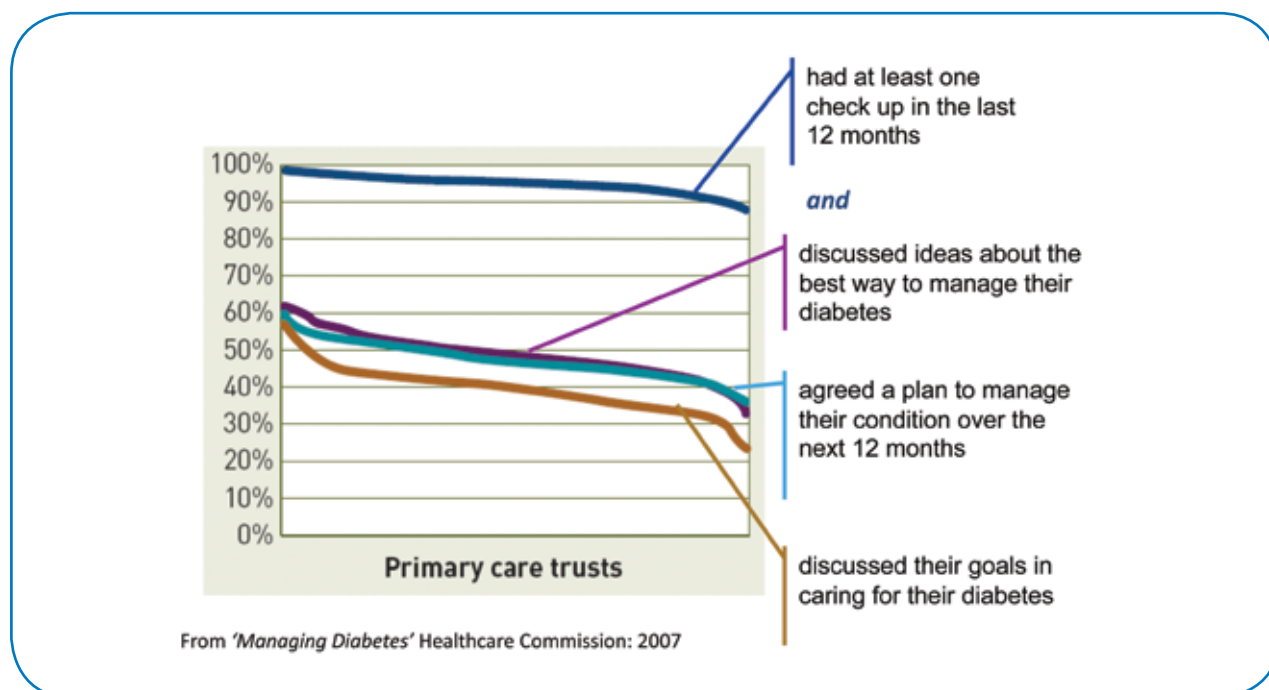


The green wavy line represents the ups and downs of daily life, when the person is managing their condition and their life, away from contact with health and social services. The vertical orange lines represent these contact points and demonstrate that not only are these contacts short (3 hours versus 8,757 hours of self care) but they are often arranged at regular intervals, unrelated to real life events or the needs of the person involved.

- 31 Royal College of General Practitioners.(2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk
- 32 Healthcare Commission. (2006). *Diabetes: The Views of People with Diabetes. Key Findings from the 2006 Survey*
- 33 Kripalani S, Yao X, Haynes RB. (2007). *Interventions to Enhance Medication Adherence in Chronic Medical Conditions: A Systematic Review*. *Arch Intern Medicine*; 167(6):540–549
- 34 Vrijens, B, Vincze G, Kristanto P, Urquhart J, Burnier M. (2008). *Adherence to Prescribed Antihypertensive Drug Treatments: Longitudinal Study of Electronically Compiled Dosing Histories*. *British Medical Journal*; 336:1114–1117
- 35 Benner, JS et al. (2002). *Long-Term Persistence in use of Statin Therapy in Elderly Patients*. *JAMA*; 288: 455-461
- 36 Department of Health. (2005). *MORI Survey: Public Attitudes to Self Care Baseline Survey*
- 37 Richards N, Coulter A. Picker Institute Europe. (2007). *Is the NHS Becoming More Patient-Centred? Trends from the National Surveys of NHS Patients 2002–7*

The Healthcare Commission survey³⁸, showed that this contact time is often spent neither efficiently nor effectively in terms of supporting self care (Figure 3). Whilst the UK does very well (as compared with other countries) to ensure that the vast majority of people with diabetes have an annual surveillance review, these reviews do not, in many cases, consist of a constructive discussion that engages the person in planning their own care or supports them to manage their own condition. As illustrated in the graph below, although 95% of people with diabetes, for example, are seen annually, only 50% discuss a plan to manage their diabetes and less than 50% discuss their own goals for self management.³⁹ Half the current time devoted to routine care is thus wasted. The YOC programme set out to deliver something more effective via care planning.

Figure 3: Diabetes care: The percentage of adults who report that they...



The Year of Care approach

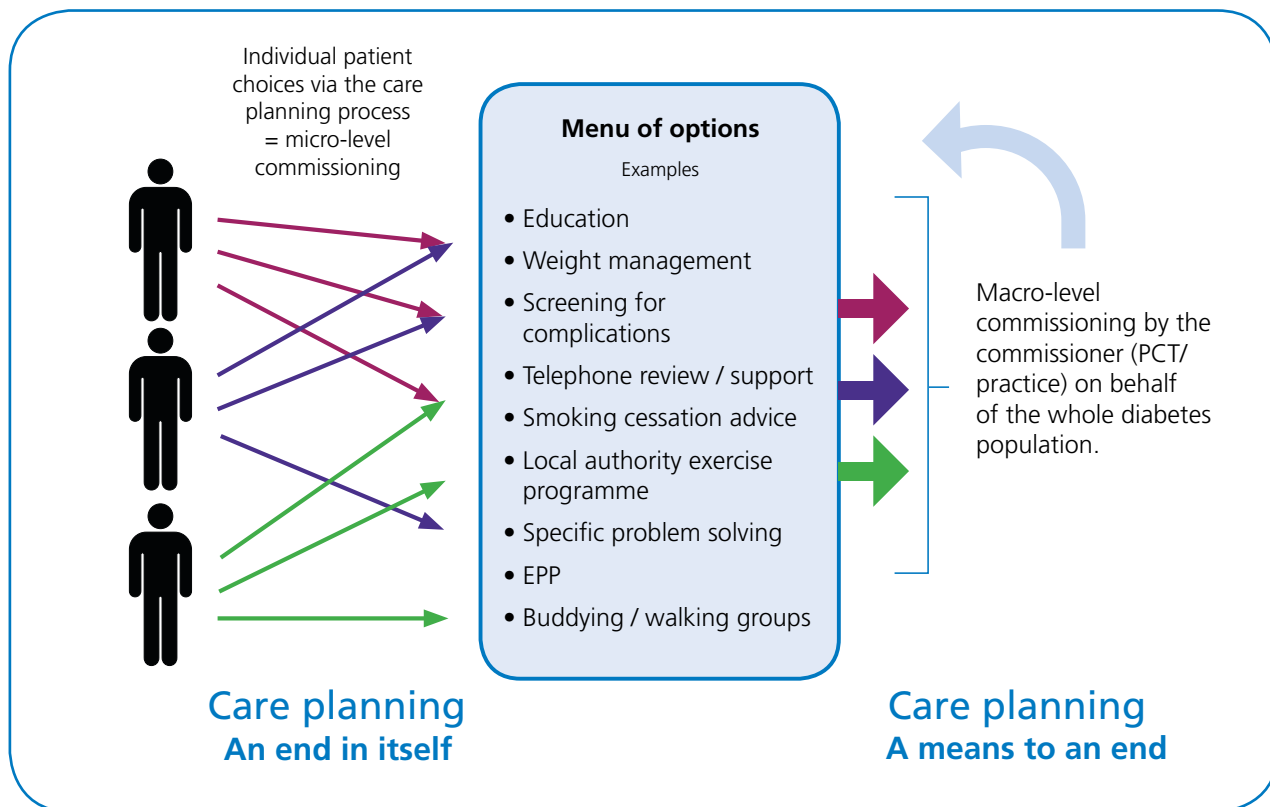
The YOC approach puts people with LTCs firmly in the driving seat of their care and supports them to self manage. It transforms the diabetes annual review, which often simply ticks off the tests that have been done, into a constructive and meaningful dialogue between the healthcare professional and the person with diabetes. As illustrated by the diagram overleaf, it does this:

- **firstly** making routine consultations between clinicians and people with LTCs truly collaborative, through care planning,
- and **then** ensuring that the local services people identify as needed to support them are recorded and available, through commissioning (Figure 4).

38 Healthcare Commission. (2007). *Managing Diabetes: Improving Services for People with Diabetes. Service Review*

39 Healthcare Commission. (2007). *Managing Diabetes: Improving Services for People with Diabetes. Service Review*

Figure 4: YOC – linking care planning and commissioning



Within this model, care planning is not only a means to make better use of limited NHS contact and a desirable end in itself, but also a means to better commissioning (macro-level) of the community services that can support the person in achieving their goals and action plans identified at their care planning consultation (micro-level). As such, the integrated YOC approach has multiple benefits, for people with diabetes and other LTCs, organisations and professionals within the healthcare system (Table 1).

Table 1: Benefits of the YOC approach

Benefits to people with long term conditions (LTCs)

- Involvement in decisions about their care
- A better understanding of their condition
- Respect for and recognition of their everyday work to self manage
- Tailored support to increase confidence and skills in self management
- Consistency and continuity of care – the person with diabetes is the most consistent provider of their own care
- A central role in service planning, and agreeing what local care should look like
- Information and signposting to local support services

Benefits to clinicians

- More satisfying consultations
- A lever with commissioners to agree more time with patients
- Commissioning influenced by genuine clinical data
- Services commissioned that people with diabetes will use
- Better outcomes for people with LTCs
- A new and interesting skill set
- A lever to improve clinical IT and drive quality improvement
- Less inappropriate use of medication

Benefits to commissioners

- Provides the framework for personalised care in LTCs outlined in the White Paper 'Liberating the NHS'
- Complete fit with QIPP
- Provides information needed to commission services that people want and clinicians value
- Greater value for money, as services provided meet individual needs and deliver improved health outcomes
- Less medication wastage
- Increases effective self management and addresses local need
- A constructive environment to work with clinicians
- A detailed understanding of pathways and costs as the basis of new local currency
- A stimulus to the whole healthcare community to redesign services for LTCs, ensuring the right care is provided, in the right place, at the right time, by people with the right skills, with the right funds
- Provides a long term, sustainable approach to reducing the burden of LTCs on local resources
- A positive impact on other local and national drivers, such as reducing acute admissions and improving the patient experience

Chapter 3: Year of Care pilot programme, governance and evaluations

This chapter describes what was involved in the Year of Care (YOC) project, how it was organised and how it was evaluated.

Key points

- The YOC pilot programme was a feasibility exercise to discover how to deliver better support for self management (SSM), as part of mainstream NHS care. Evidence of the effectiveness of SSM was already well documented.
- The programme was implemented in three diverse health communities and extrapolated to other interested sites across England.
- The governance increasingly reflected the principles of collaborative care planning itself; with partnership-working between the central steering group and local delivery teams.
- Regular evaluation provided a wealth of useful material. Many lessons were also learnt about *evaluating* complex and evolving interventions and cultural change.
- The burden of data collection, at times jeopardised the delivery of the intervention itself.
- PCRS-UK, a new validated tool, was used for the first time in the UK and proved useful in supporting teams to assess their organisational readiness to support self management.

YOC programme is a partnership between Diabetes UK, NHS Diabetes, the Health Foundation (THF) and the Department of Health (DH).

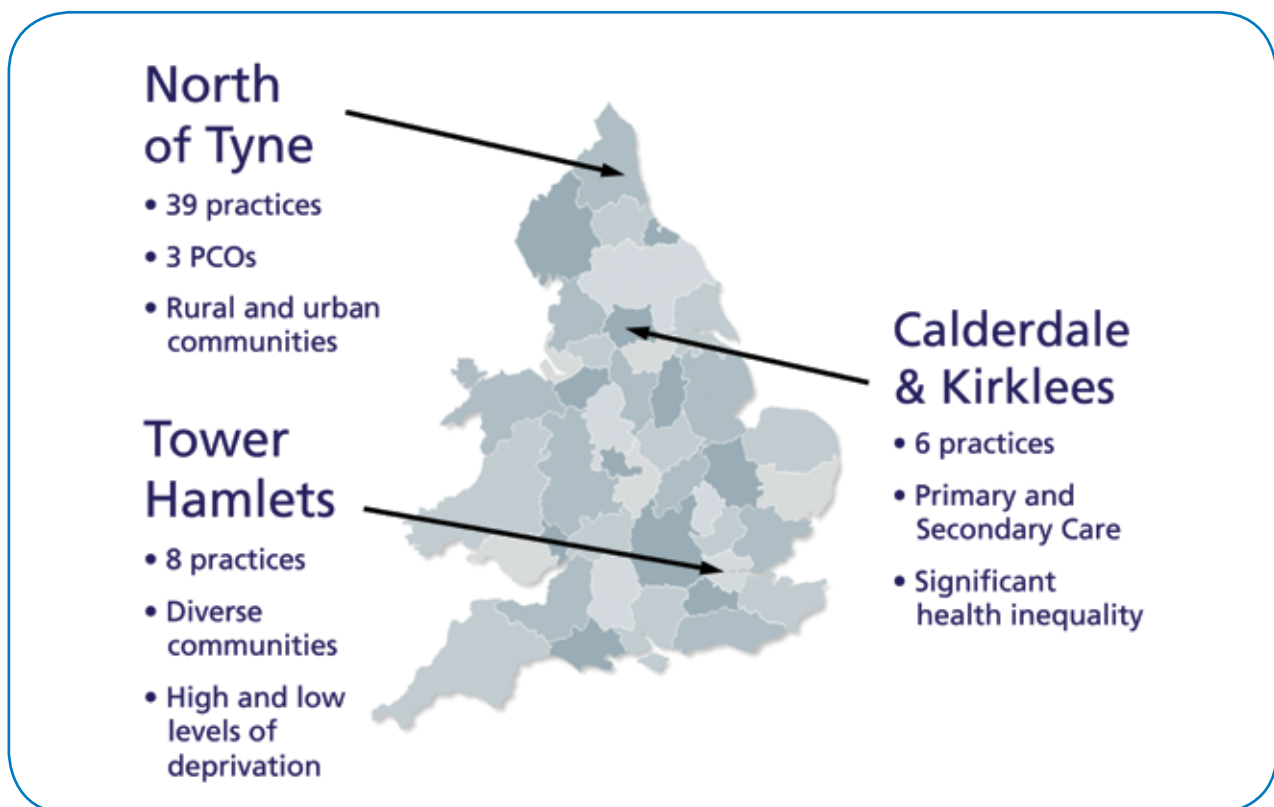
Within its overall aims, the programme set out with six 'programme questions' in mind. These were developed by the partners, including policy leads from Choice, Long Term Conditions, and Commissioning within DH, the research lead from NHS Diabetes, members of the national diabetes user group, The Health Foundation and Diabetes UK. All partners contributed funds for different components.

The six programme questions

- How to establish care planning in routine use.
- How to identify sections of the local population by potential need for services to support self management.
- How to systematically link individual choices / actual service use into population level commissioning.
- How to develop new and existing providers to support self management.
- What are routine care costs before and after the YOC approach?
- What does it mean for policy?

Three diverse pilot sites (Figure 5) were recruited by a competitive selection process to gain innovation and spread in 2007; NHS Calderdale & Kirklees, NHS North of Tyne and NHS Tower Hamlets. Each brought different skills and experience. You can read more about these sites and their journeys in full in the *Year of Care Pilot Site Case Studies* accompanying this report.

Figure 5: Map of pilot sites within the pilot phase of the YOC Programme



The programme lasted three years and was divided into two phases. Year 1, the Feasibility Phase, tested the feasibility of the concept that all components of the model could be put in place. Years 2 and 3, the Implementation Phase, tested implementation on the ground. The programme sought answers to the six project questions through a sustained, integrated programme of work and evaluation, and focussed on the different components of the approach (care planning, commissioning, IT and provider development) at different sites, at different times, as appropriate. In the implementation phase, a National Training Team (now the National Training and Support Team) was commissioned to deliver quality assured training and to develop a quality assured 'Train the Trainers' programme to support roll-out for trained sites.

Governance

The YOC programme has been guided by its Partnership Board, comprising representatives from each partner organisation and was supported both strategically and operationally by a Programme Board, whose membership evolved, as necessary, to include project managers and the training lead, and included partners and local Senior Responsible Owners (SROs) throughout. The programme was managed by a central team, comprising the YOC Programme Manager, Clinical Lead and representatives from the partner organisations.

Each pilot site developed a work plan, reporting on progress regularly. Learning events were used to develop models for delivery, provide support, and share experiences and good practice. Satellite projects and work streams were commissioned to meet specific needs and demands of the core programme. Pilot site learning was supplemented by activity with other health communities that tested transferability. To date, 15 sites (including the three pilot sites) have started to, or are delivering, the key components of the programme, using nationally quality assured local trainers.

An Evaluation Steering Group commissioned and oversaw parallel evaluations from external organisations which shaped the development of the project and its delivery throughout. This included separate evaluations of the two phases of the project by Tribal Consulting (now Capita Health), and in depth research with stakeholders at the end of each of the three years of the project by experienced qualitative researchers identified by NHS Diabetes. All external evaluation reports can be found on the YOC website. A number of local qualitative and quantitative service development and audit projects also enhanced the findings.

Evaluation: methodology and approach

Year 1: Feasibility Phase

Tribal Consulting, an independent research group, secured the one year contract to test the feasibility of preparing for a YOC programme across three pilot sites, and to agree a set of research instruments that could be used to measure the process and impact of the intervention over two years of implementation.

The methodological framework recommended was *Realistic Evaluation*⁴⁰. This approach recognised the constantly changing context that often surrounds complex interventions of the nature of YOC, and sought to understand how context and complexity impacts on process and outcomes.

Over five site visits were conducted at each pilot between November 2007 and August 2008. Data were collected by one-to-one interviews with key stakeholders at the sites as well as by group discussions, working groups, learning events, email correspondence and an analysis of written material produced by the individual pilot sites. The researcher regularly reported back to the central team, enabling them to react quickly to emerging findings and tailor support.

The Feasibility Phase evaluation report⁴¹ recognised the sheer volume of work undertaken at each site to prepare for YOC. Importantly, it noted that one size did not fit all and described how different routes and approaches were used in getting from A to B. It also reported that key stakeholders had been easily engaged locally and that YOC fitted well with contemporary policy and proved to be an attractive mechanism for developing local services. Tribal Consulting concluded that it was feasible for individuals and organisations to prepare services for YOC.

At this stage, a set of measures was agreed to record the process and impact of the project (Appendix 1). These included patient experience and satisfaction, service development and implementation of care planning and commissioning, costs of care delivered and services used, clinical outcomes and indicators. A number of these tools had not been used before in similar contexts and the exploratory nature of their use was recognised.

40 Pawson, R & Tilley N. Sage. (1997). *Realistic Evaluation*.

41 Tribal Consulting. (November 2008). *Evaluating Pilot Sites as They Prepare for the Year of Care: Final Project Report*.

Table 2: Measures used within the YOC pilot phase programme

Measure	Purpose
National evaluation	
Primary Care Resources & Supports for Chronic Disease Self Management (PCRS UK)	A self assessment, feedback and quality improvement tool for use in primary care settings
Healthcare Commission Survey (HCC) (Adapted)	To assess whether patients are receiving the care, treatment and information they need from their local services to manage their diabetes
Consultation Quality Index (CQI-DM)	To explore the patients personal experience of the consultation (structure, process and outcome)
Diabetes Treatment Satisfaction Questionnaire (DTSQ)	To identify patients satisfaction with overall diabetes treatment
Quality of Life (EQ5D)	A measure of health status providing a single index value
Biochemical indices	To assess change in key indicators across time
Client Services Receipt Inventory (CSRI)	To capture patterns of service receipt, which are used as proxy indicators for costs

The PCRS-UK (Primary Care Resources and Supports) is a tool specifically developed to support delivery of the Chronic Care Model (CCM).⁴² It is designed to enable self-reflection by a practice or clinical team, both on how well they support individuals to self care, and also how well the practice infrastructure is organised to facilitate this. PCRS⁴³ is a well-validated tool developed by the Robert Wood Foundation, and includes a small number of words with significant USA healthcare meaning. Tribal Consulting negotiated UK substitutions and the changes were piloted successfully in practices in Tower Hamlets, and subsequently recognised by the licensees as PCRS-UK.⁴⁴ The results of use of the PCRS-UK in the YOC Project have been presented nationally (See Appendix 3) and the potential to use this as a facilitation tool is shown in Figure 6.

42 Wagner, EH, Austin BT, Von Korff M. (1996). *Organising care for patients with chronic illness*. The Millbank Quarterly. 74(4) 511–44

43 PCRS. (2006). *Assessment of Primary Care Resources and Supports for Chronic Disease Self Management*. developed by the Robert Wood Johnson Foundation Diabetes Initiative. March. (Online) Available from http://improveselfmanagement.org/pcrs_background.aspx

44 PCRS. (2008). *Assessment of Primary Care Resources and Supports for Chronic Disease Self Management*. UK version PCRS (see previous footnote) adapted for use in UK in June 2008

Figure 6: A North Tyneside Practice

Using the PCRS-UK to demonstrate changes in practice readiness to support self care over two years, at an individual (left) and organisational level (right).

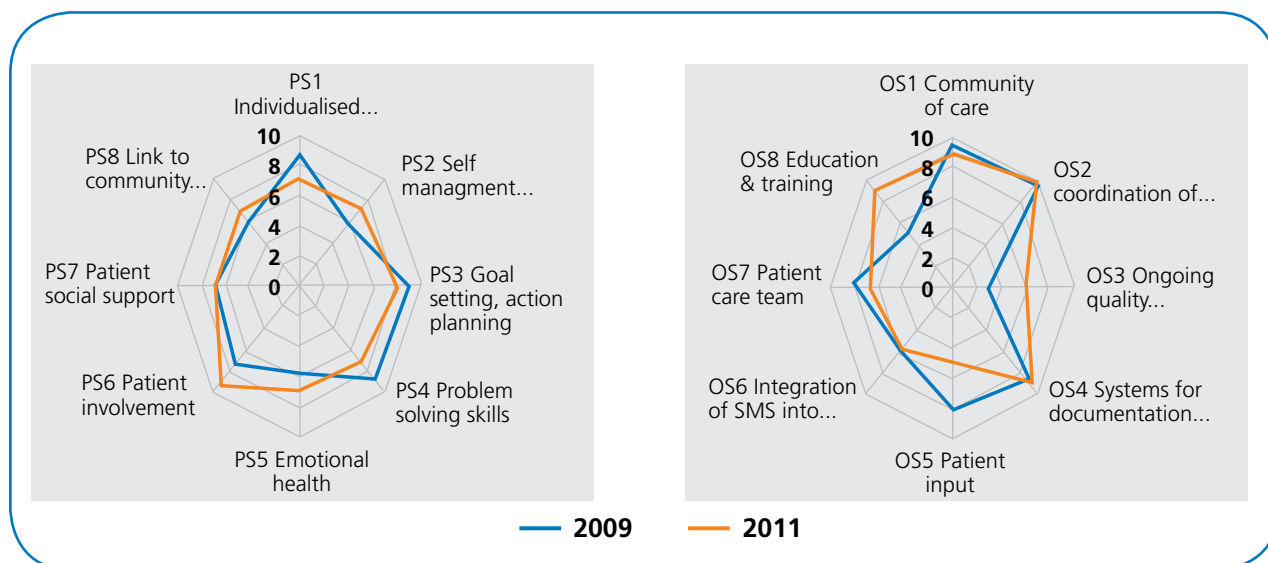


Figure 6 Legend

Patient support		Organisational support	
PS1	Individualised assessment	OS1	Continuity of care
PS2	Self management education	OS2	Coordination of referrals
PS3	Goal setting, action planning	OS3	Ongoing quality improvement
PS4	Problem solving skills	OS4	Systems for documentation of SMS
PS5	Emotional health	OS5	Patient input
PS6	Patient involvement	OS6	Integration of SMS into primary care
PS7	Patient social support	OS7	Patient care team
PS8	Link to community resources	OS8	Education and training

Towards the end of Year 1, it became clear that the burden of data collection at practice level was in danger of derailing the capacity of practices to deliver the care planning intervention itself. Tower Hamlets opted to commission Picker Institute to develop a set of relevant questions which were adapted from the Healthcare Commission⁴⁵ questions used in the 2006 national diabetes survey that could be used as a baseline. It was to be administered by telephone across a wider group of local practices, some involved in YOC and some not. Eventually, owing to time needed to solve information governance challenges, this was administered once only by post and unfortunately had no clear link with the stage of development of the practices involved. This made it difficult to compare findings across sites (Appendix 4: Relevant data from survey collected by Tribal Consulting and Picker Institute for the YOC pilot sites).

45 Healthcare Commission. (2006). *Diabetes: The Views of People with Diabetes. Key Findings from the 2006 Survey*

Years 2 and 3: Implementation Phase

In August 2009, Tribal Consulting was commissioned to conduct a qualitative and quantitative evaluation of the implementation process and impact of YOC over Years 2 and 3, the Implementation Phase. The approach to evaluation shifted to an emphasis on data collection and less 'hands on' contact with pilot sites. Staff changed and organisational memory was lost. However, a substantial piece of qualitative work, including interviews and focus groups, and highlighting important risks, conclusions and recommendations for the Programme Board was produced at the end of Year 2.⁴⁶ These recommendations significantly shaped the development of the programme going forward.

By Year 3, the final year of the project, a large quantity of data was available. However, a number of data issues were uncovered. The questionnaire data had not been reliably identified to the three planned time points (Baseline, Year 1 and Year 2) (Appendix 1) and only a small number of individuals could be identified (with their approval) who had participated in the care planning process more than once. Notwithstanding the data collection issues, the gradual introduction of care planning into practices, and the reality that it takes 12 months for all patients in a practice to have taken part in an annual care planning consultation, even when all systems and processes are in place, meant that it was difficult to report a patient's journey and experience and therefore the impact of the intervention at an individual level. Another challenge was that with additional and independent development activity happening in local areas during the implementation of YOC, it was unclear how the data being reported related to the intervention itself. That is to say, it was difficult to attribute results specifically to the YOC.

Of the new instruments, the CQI-DM had not been collected in sufficient volume, and not been linked with specific clinicians to enable useful conclusions to be drawn. As a result of this, the intention to have data from patients on their experience of the care planning consultation itself was not achieved, and this had to be deduced from other sources. The CSRI, which had been successfully used to record service use in mental health and required telephone administration, proved to require a validation phase before it could be transferred to the very different world of service use in diabetes. And the PCRS-UK, which had been so effectively identified as a relevant tool in Tower Hamlets, was not analysed as intended in the other pilot sites by the evaluators, although the YOC team subsequently rectified this problem by commissioning supplementary research in a number of practices.

Finally, new research staff in the evaluation team lacked sufficient knowledge and context to produce end of project case studies. Resources were therefore diverted to enable case studies to be produced by the experienced researcher who conducted the stakeholder research (next section). The experience of individual practices in introducing care planning and the costs before and after the intervention were achieved by practice visits and analysis by one of the YOC project managers with extensive experience of primary care, to provide consistency across sites. Biomedical data was obtained from special collections set up locally to monitor service agreements.

⁴⁶ Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the 'Year of Care for Diabetes' Project: Interim Report*. November

Stakeholder interviews

An additional evaluation from the strategic perspective was based on stakeholder interviews, and was carried out in three waves. These reports proved invaluable to the Board at the end of each of the first and second years.⁴⁷ They helped to consolidate learning but also brought other issues to the surface for action or reflection. For instance, the need for the pace to slow after the hectic set up stage, the issue of demonstrating applicability in diverse communities, the need to articulate the commissioning task as clearly as the care planning task were important issues that were flagged. The relative loss of momentum and reduced number of learning sets were also highlighted in Year 2.

The third wave report,⁴⁸ written at the end of the project, was used to reflect on the project as a whole and to develop themes that had wider relevance. It was decided to draw out the themes that seemed most relevant to learning how a complex programme such as YOC can be implemented in a complex environment like the NHS, and the challenges associated with this. These issues are outlined in Chapter 17.

Deep dives

North Tyneside and Tower Hamlets both used the process of 'deep dives' into practices, every year in Tower Hamlets, and during the last year in North of Tyne carried out by the clinical leads and project managers. During the final months of the project, sample visits were made by one project manager to all sites to validate and identify the whole journey for practices. Together with the data from interviews and focus groups these expert assessments enabled a picture to be built up of what might reasonably be expected in a new practice that started from scratch.

47 Sweeney G. (2009). *Year of Care Review Report*. February AND Duquemin A. (2010). *Views And Decisions For Consideration By Year Of Care Programme Board: Wave 2 interviews with Key Stakeholders*. January

48 Duquemin A. (February 2011). *Year Of Care: Reflections On Introducing A Complex Intervention Into A Complex Environment*

Chapter 4: Care planning – implementation and issues

This chapter describes the Year of Care (YOC) model of care planning, and how it was developed across the three pilot sites. Greater detail is available in the companion case studies for each pilot.

Key points

- Care planning is an example of putting self management support into practice, in a systematic way, as part of routine care for people with long term conditions (LTCs).
- The 'Care Planning House' illustrates that the collaborative consultation cannot take place without addressing the practice or clinic infrastructure that surrounds it.
- Introducing care planning involves significant cultural / attitudinal as well as practical change for both practices and people with diabetes.
- Introducing YOC needs senior support *'right from the top, right from the start, and right the way through.'*
- *And* local facilitation and coordination.
- The programme learnt by doing, both locally and centrally, by sharing and reflecting on practice and by developing tailored solutions to overcome the barriers and dilemmas that arose.

What is care planning?

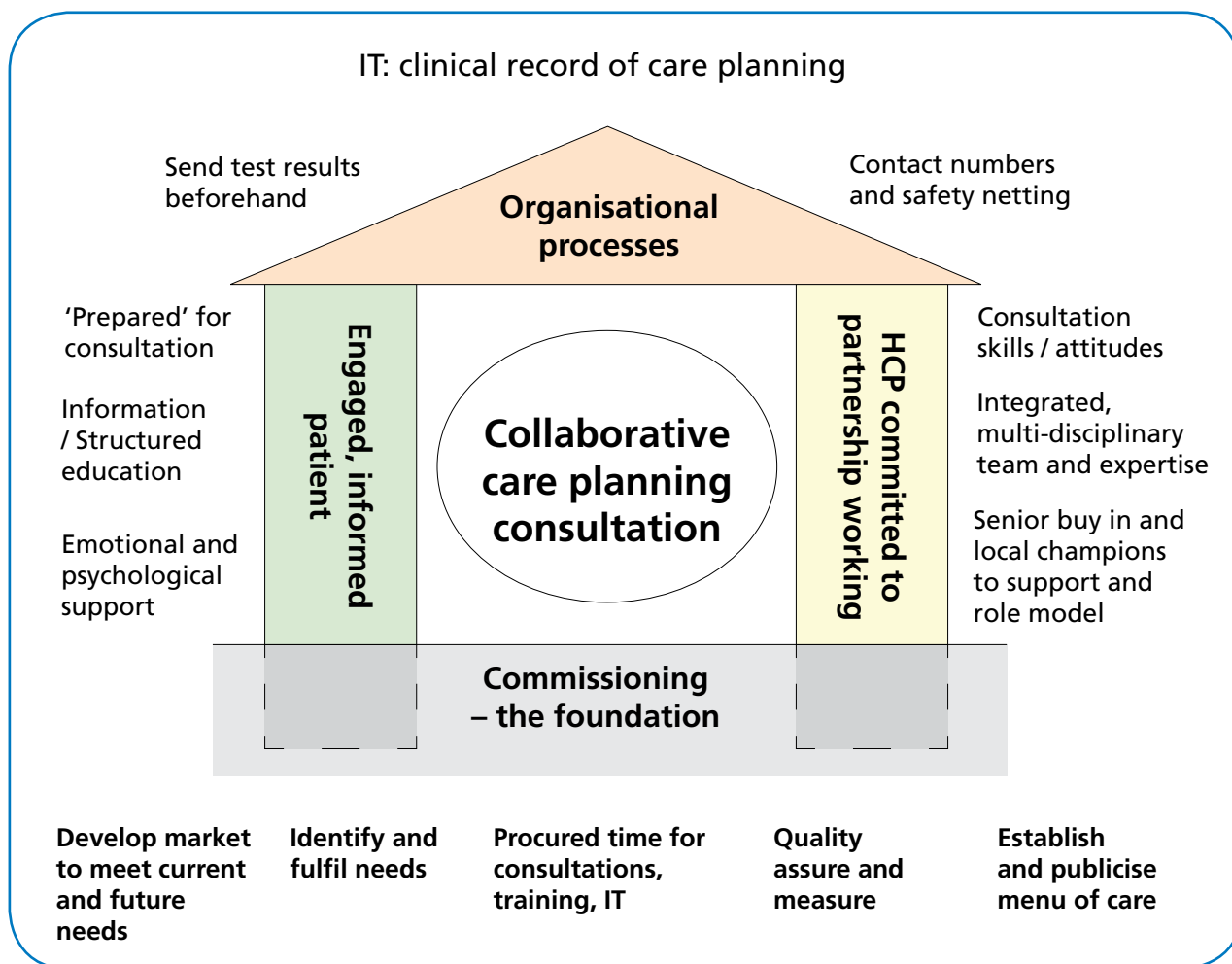
“Care planning is a process which offers people active involvement in deciding, agreeing and owning how their diabetes will be managed. It is underpinned by the principles of patient-centredness and partnership working... It is an ongoing process of two-way communication, negotiation and joint decision-making in which both the person with diabetes and the healthcare professionals make an equal contribution to the consultation.”

Department of Health and Diabetes UK⁴⁹

The National Diabetes Care Planning Working Group developed a model for an effective care planning consultation, and the YOC Programme validated its practical application and identified the infrastructure to support this. This is encapsulated in the **YOC, Care Planning House** (Figure 7).

49 Department of Health and Diabetes UK. (2006). *Care Planning in Diabetes*. Care Planning Working Group

Figure 7: The Care Planning House



The core elements of care planning, described in *Getting to Grips with YOC*⁵⁰, are referenced as guidance in the NICE Quality Standard⁵¹ to implement care planning. The philosophy, rationale and practice of a care planning consultation are detailed in *Partners in Care – A Guide to Implementing a Care Planning Approach to Diabetes Care*.⁵² The evidence base for the components to deliver care planning are found in Graffy et al.⁵³ A further discussion of underpinning theoretical principles is to be found in YOC reports.⁵⁴

The House acts as a metaphor as well as a framework, emphasising the importance and inter-dependence of each element – if one element is weak or missing the service is not fit for purpose. The key components are the person with diabetes being engaged and informed, working with healthcare professionals who are committed to partnership working. The framework shows that this will only occur in practice if there are sound organisational processes that facilitate their interaction, built on the foundations of robust commissioning processes.

50 Year of Care. (2008). *Getting to Grips with Year of Care: A Practical Guide*

51 National Institute for Health and Clinical Excellence (NICE). (2011). *Diabetes in Adults Quality Standard*. (Online) Available from www.nice.org.uk/guidance/qualitystandards/diabetesinadults/diabetesinadultsqualitystandard.jsp

52 NHS Diabetes. (2008). *'Partners in Care' – A Guide to Implementing a Care Planning Approach to Diabetes Care*

53 Graffy J, Eaton S, Sturt J & Chadick P. (2009). *Personalised Care Planning for Diabetes: Policy Lessons from Systematic Reviews of Consultation and Self-Management Interventions*. *Primary Health Care Research & Development*, 10, 210-222

54 Doherty Y, Ludbrook S, Turnbull R, Lewis-Barned N. (2011). *Diabetes Year of Care: The Key Drivers and Theoretical Basis for a Shift in Diabetes Care*. www.diabetes.nhs.uk/yearofcare AND Ludbrook S, Doherty Y, Turnbull R, Lewis-Barned N. (2009). *What do Patients and Clinicians Think of Year of Care* (Abstract 296) *Diabetic Medicine*. 26. Supplement 1. 126

In Phase 1 (feasibility), pilot sites found that there were a variety of ways to support the key components of the House. The text around the House shows examples of the key issues that need to be considered under each component.

A key element in the structure developed by YOC is the concept of two visits; the first to gather traditional biomedical information with a view to sharing it with the person with diabetes. This should take place before the second care planning consultation when this can be integrated with the person’s experience of living with diabetes to form a shared agenda. Figure 8 demonstrates how this is a practical reflection of the core principles of collaborative care planning at the centre of the House.

Figure 8: How the two visit consultation reflects the core principles of care planning



In the Implementation Phase, the successes and challenges emerged. Small natural ‘experiments’ occurred where some things had gone well or less well. Thus, by Year 3, the Programme had a clearer idea not just of what the key components of the House framework should be, but of what works and what is less successful when introducing it into practice. This iterative process corroborated the findings in the literature⁵⁵ with respect to the barriers to introducing SSM in practice. These are described as ambivalence by staff about their role in SSM, lack of the new clinical skills and inappropriate organisational infrastructure or incentives. The YOC training and support programme, based on sound educational theory,⁵⁶ empirically developed and addressed these barriers.

The comprehensive RCGP care planning guidance document⁵⁷ provides practical examples and key tips for how to introduce care planning at practice level described as ‘walking around the House’.

55 Blakeman T, Macdonald W, Bower P, Gately C. (2006). *A Qualitative Study of GPs’ Attitudes to Self-Management of Chronic Disease*. Br J Gen Pract. Jun;56(527). 407–14

56 Knowles, MS. (1998). *The Adult Learner: The Definitive Classic in Adult Education and Human Resource Development* (5th edition). Houston, Texas: Gulf Publishing

57 Brookfield SD. (1991). *Understanding and Facilitating Adult Learning: A Comprehensive Analysis of Principles and Effective Practices*. San Francisco: Jossey-Bass

57 Royal College of General Practitioners.(2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk

How we did it

Rich experience and learning occurred across all pilot practices and PCTs during the three years of the pilot project. For a more detailed description, we recommend you read the YOC pilot site case studies.

Local aspirations and set up

Each pilot site applied to join the YOC Programme because they saw it as an opportunity to address local issues of importance to them.

NHS Calderdale & Kirklees were already involved in a programme to improve services for their large and increasing population of people with diabetes, as this had been identified as poor by national benchmarks.⁵⁸ They were also keen to address the new national target for ensuring that everyone with a LTC received a care plan. They saw YOC as a means to support both these local objectives.

In Tower Hamlets, diabetes was an even bigger challenge, with large inequalities in general practice and across their very diverse community. They were already part of *Making the breakthrough*⁵⁹, a project to reduce inequalities across diverse ethnic communities, and were struggling to find practical solutions to engage people with diabetes. Both these PCTs had poorly developed basic diabetes services.

North of Tyne, in contrast, had a long history of well-structured and integrated diabetes services, better outcomes and among the highest scores in England for people with diabetes reporting involvement in discussing their goals and ideas for managing their diabetes.⁶⁰ Primary and specialist care had a long-standing joint interest in patient centred care. They saw YOC as a way of renewing their interest in this and achieving further improvements in patient experience.

Each site used financial incentives to involve practices. Owing to the enormity of the task and the challenge in their area, Tower Hamlets selected a group of eight practices within one locality, which had both some of the most and least deprived populations in the country. In Kirklees a new diabetes service was being incentivised to work much more closely with specialist care, and six volunteer practices (three in Calderdale and three in Kirklees) agreed to take part in what was seen as a specific project to assess the introduction of care planning and care plans. The North of Tyne pilot worked with practices in two of their localities. In North Tyneside, a majority of local practices wanted to be involved and this was considered feasible because of previous grass roots work and the potential to demonstrate care planning over a complete health community. West Northumberland, with its large rural population joined the programme a few months later. Here, there was a long tradition of joint audit and quality improvement. Care planning was introduced as part of this, with a one off set up payment from service improvement funds.

Year 1: Feasibility Phase

While all sites set up steering groups, sub groups and appointed project managers, significant variations emerged quite early. Some of the detailed activities are described in *Getting to Grips with Year of Care*.⁶¹

North of Tyne built on previous joint working between primary and specialist care, and the experience of a pioneer practice which had sent out tests results to people with diabetes before the consultation. They focused on training based on facilitating practice organisation and the House model. Practices described the constructive changes they were making, at the well-attended follow up meetings. Structured interviews with people with diabetes and professionals validated the approach and the immediate improvement in experience for both.

Semi-structured interviews were carried out with people with diabetes and healthcare professionals either immediately after the clinic or for professionals as soon after as practical, towards the end of Year 1. A thematic analysis of barriers and facilitators and the personal reflections supported the further development of the

58 Healthcare Commission. (2007). *Managing Diabetes: Improving services for people with diabetes*. Service Review

59 Tower Hamlets. PCT Operating Plan 2008/09: www.towerhamlets.nhs.uk

60 Healthcare Commission. (2006). *Diabetes: The Views of People with Diabetes*. Key Finding from the 2006 Survey

61 Year of Care. (2008). *Getting to Grips with Year of Care: A Practical Guide*

training programme. It was shared at a learning event providing a positive evidence base for the new processes and procedures that were being put in place across all the pilots.⁶²

Tower Hamlets had to tackle a wide range of issues and worked individually with practices in 'meet and greet' events, carried out an extensive patient participation exercise, based at practices where lunchtime meetings sometimes attracted 100 or more participants. This was helped by the well-networked Patient and Public Involvement (PPI) lead who sat on the local Project Board. The team identified a range of approaches that would be needed to gain greater involvement with their diverse local population. They also worked hard on the administration of care planning, including the challenge of IT in 'paperless practices', and recognised the difficulties of working in this way with people with extremely poor health and language literacy.

Calderdale and Kirklees rapidly identified actions and plans for their local practices and populations based on their previous experience. Some practices used YOC as an opportunity to employ a wider multidisciplinary team within the practice with the aim of providing better and more coordinated services for their practice population in a 'one stop shop' format. Initially, practices independently adopted a traditional approach to research, dividing their diabetes populations into those that would and those that would not receive the new approach to consultation, with individual consent. Training for staff in motivational interviewing was commissioned from the local Higher Education Institution (HEI). In parallel, the project began a systematic local needs analysis with a focus on social marketing which will be discussed in further detail in Chapter 12. Many of the components of the care planning were put in place early; however, this meant that some of the components were not yet in place to address the everyday needs and practicalities of primary care. This made their experience somewhat different to the other sites and the challenges and learning derived from their experience highlighted issues for the programme to address, from which the other sites benefited.

Years 2 and 3: Implementation Phase

Much of the most valuable learning came from this phase. The YOC Programme Board, which now included the senior responsible owners (SROs) from the sites, agreed that, at least initially, it was the job of local sites to get on with implementation. The central team spent some time visiting and listening to the experience of other communities who were trying to implement it elsewhere. These 'early implementers' benefited from the written guidance from the first year (*Getting to Grips with YOC*⁶³) but without the intense period of model development and self-reflection that had taken place for the pilot sites themselves. This learning is summarised in the next chapter.

No further extra funding was available for local sites, but they were all enthusiastic about the approach, had already identified local benefits, and each committed resource to support local development. However, the conclusion from the parallel evaluations was that the pace of the project slowed in Year 2. Motivation was also hit, as the realities became clear. In two of the pilot sites (North of Tyne, Calderdale and Kirklees), the initial verve and fervour of the first year was less evident, not for want of enthusiasm but for the inevitable dampening as a result of daily workload for all those involved in the programme. This was exacerbated by the lack of a full time worker on the project to manage the project comprehensively on a day to day basis. The difference in previous full time project management support was stark. The need to maintain momentum was a recognised challenge in North of Tyne and a meeting of the steering committee was held to develop a work plan.⁶⁴

Not all people with diabetes in YOC practices were clear about the new ways of working, and recognised that this was not simply a project to be introduced, but a culture change that would take years to embed. However the issues that were identified in this first implementation year were then successfully addressed during the final year; with the result that care planning became the norm in all pilot sites with the exception of Calderdale, a majority of the new sites, and an effective training and support team was in place for the benefit of new centres.

62 Ludbrook S, Doherty Y, Turnbull R, Lewis-Barned N. (2011). *What do Patients and Clinicians Think of Year of Care* (Abstract 296) *Diabetic Medicine*. 26. Supplement 1. 126

63 Year of Care. (2008). *Getting to Grips with the Year of Care: A Practical Guide*

64 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the 'Year of Care for Diabetes' Project Interim Report*. November. (p71)

Two central support initiatives were started during this phase.

- **Training**

With the recognition of the importance of training, the individuals who had developed the North of Tyne approach to training were funded to become the National Training and Support Team. The basic training modules were enhanced and continuously improved in the light of feedback. Initially this was provided by new practices within the pilot sites, but was then tested elsewhere as more and more interest was shown in the approach (details of the training programme are provided in Chapter 7).

- **Information technology**

The issue of lack of appropriate IT was repeatedly identified as a barrier to embedding care planning. No existing practice system was able to record the key components of care planning such as goals and action plans in a structured way. An opportunity arose to work with an IT initiative in Yorkshire and Humber SHA to develop the key fields that were required to support the care planning consultation using the 'laboratory' of the SystmOne record. (Details of the further development and products are available in Chapter 6).

Pilot site variation

North of Tyne, in contrast to the other sites, found itself looking out rather than looking in. That is to say the limited time available to members of staff was spent more on national than local activities. Three factors contributed to this change. In addition to the reduced hours of the YOC project manager, key members of the specialist team who worked closely with individual practices left and were not replaced for financial reasons. Others were seconded to develop the National Training initiative. So, both project activity, such as local project steering group meetings and direct contact with practices declined. In retrospect, the local team feel that more would have been achieved if there had been more feedback of data, practice contact, local learning sets and support where specific practice issues were identified. They wonder if it would have been more sensible to start with fewer practices. Despite this, a considerable amount was achieved with a majority of the 28 practices able to slowly and systematically redesign the way they worked, reporting on the positive benefits to all, and report that this was now the norm.

“The changes have enabled the nurse practitioner more time to discuss diabetes care and planning rather than having to do BP, etc whilst talking to the patient. The patients have given positive feedback about receiving their results prior to their annual review. The nurse practitioner feels she has more time to discuss the patient’s diabetes care and motivating them to make any changes. We feel the changes have all been positive and will not be changing back to the old style of working.”

*Practice response*⁶⁵

In contrast, in Tower Hamlets, the steering group continued to meet regularly. A GP champion and new project manager worked intensively on issues identified by practices. Individual practices began to restructure their workforce and experimented with new ways to engage individuals. Issues were raised regularly at local GP meetings and the recognition that much more clinical training was needed began to be expressed. Gradually more practices and staff received what was now the National Training. The recognition of the central role of care planning in involving people in their care led to new commissioning arrangements across the PCT, putting care planning at the centre of 'care packages' for both diabetes and cardiovascular disease. These were introduced in phases as part of the Integrated Care Pilot from September 2009 to April 2010, using tools and resources developed within the YOC pilot.

65 Year of Care. (2011). 'Deep Dive' submitted response to programme

“Year of Care is working well in Tower Hamlets... There has been a great deal of self-reflection and debate as to what works well and what does not. There is great commitment evident not only from the senior staff at the PCT, a highly active and involved Project Board, a project manager who is proactive and supportive to the practices, but also, and crucially, the staff at all levels in the eight practices.”⁶⁶

In Calderdale and Kirklees, one practice dropped out almost immediately and another partially disengaged. The main reason given was the burden of the questionnaires, but practices where training had been entirely focussed on the motivational and behaviour change of patients and did not address professional attitudes or infrastructure, could see little value to themselves or the people with diabetes on their registers. In retrospect, it was easy to see that the training specification had been drawn up before the implications of care planning and House model had been fully articulated. The local development of a new IT template for diabetes also raised expectations that care planning would follow in practice if the new care planning templates were put into place. Finally, in Kirklees the desire to involve everyone with a LTC in care planning meant that the specific needs of each clinical setting were not addressed explicitly, and no GP champion arose to promote the new way of working in primary care.

In Calderdale, despite enormous input from the local coordinators, the PCT Board had not fully embraced the distinction between ‘care plans’ (for the coordination of care to avoid unscheduled admissions) and ‘care planning’ for those independently managing their LTCs in the community (see Figure 13 Chapter 5). They expected early and measurable reduction in service use and had not yet agreed a whole service pathway for diabetes. Tribal reported a risk that in Calderdale and Kirklees, YOC would coalesce into a small and narrow function of sending out blood results and writing down goals, without necessarily applying adequately the underlying principles of greater responsibility and partnership. The leadership was left to Kirklees who were able to identify the issues, adapt quickly, and working with a project manager with long experience of primary care, were able to refocus the project. Using carefully managed incentives and further ‘waves’ of care planning training, 83% of practices throughout Kirklees were able to start care planning with considerable success and enthusiasm, even though the formal end of the programme was approaching. At the end of the project, the later phase practices remain more engaged in the YOC approach than the original pilot group. Finally, a care planning brief ‘awareness’ module on the place of care planning and the clinical issues involved in supporting self management enabled community staff to participate in a care planning approach more successfully.

While the dominant issues in delivering the Programme’s successes were leadership, clarity of purpose, grass roots facilitation and coordination, Tribal noted that there was some inequity in the amount of resources that the three sites had directed at the project. Tower Hamlets was able to devote considerably more resources to the project than the other two sites. This had an impact on the project in a number of ways.

There is no doubt that the whole programme was able to learn from these differences. The importance of resource targeted at the needs of disadvantaged groups to kick start engagement, and the need for grass roots facilitation across the service are lessons for the successful delivery of high quality services for all LTCs, beyond the specific issues of the YOC project.

66 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the ‘Year of Care for Diabetes’: Project Interim Report*. November. (p77)

Table 3: Practice involvement in each pilot site throughout the YOC pilot phase of the Programme

	Total practices in PCT area	Original pilot practices				Roll out practices	
		Agreed at start	Working with YOC pilot Dec 2010	Tribal questionnaires	PCRS	Attended national training	Taking part in care planning (% of PCT practices) Dec 2010
Tower Hamlets	35	8	8	NA	8 (x2) 7 (x3)	28	35 34 (97%)
Kirklees	71	3 [†]	3 (1 partially)	3 (1 partially)	2	56	59(83%) Providing data
Calderdale	27	3 [†]	2	3 (1 dropped out at year 1)	2	0	2 (7%)
North Tyneside	28*	26*	23**	11	14 (x1) 8 (x2)	0	23 (79%)
West Northumberland	15	11	11	8	7 (Tribal recorded three) 1 (twice)	0	11 (73%)

* Twenty eight practices originally showed interest. Two merged during the pilot phase leaving a denominator of 26.

** Worked with team to develop national training.

† Did not receive care planning training.

Chapter 5: Care planning – discoveries and dilemmas

This chapter tackles key enablers and barriers to implementing care planning.

Key points

- Philosophy, attitudes and systems must all be addressed together to implement and sustain care planning.
- Staff need to be clear about their role if they are to fully participate.
- There must be clarity over where care planning fits in the local pathway or model of care.
- Leadership is critical to support alignment across the whole local health economy:
 - *‘right from the top, right from the start, right the way through’*
 - this must include GPs.
- Local coordination is essential:
 - to include primary care experience, a facilitative approach and partnership working
- Care planning is about cultural change and this takes time:
 - staying in for the long haul delivers
 - the Year of Care (YOC) learning now packaged by the Training and Support Team enables new sites to get up and running more quickly.

Being systematic is essential – but not enough

The first part of this section outlines why being systematic is essential; the second describes the limitations of a structured approach that doesn't embrace the philosophy.

The importance of a systematic approach to delivering care planning was described in *Getting to Grips with Year of Care*⁶⁷ at the end of Year 1. The process of the consultation itself, the surrounding infrastructure of the House, and the first step of sending test results to people a couple of weeks before the consultation came to be seen as the core aspects of the YOC approach to care planning. Providing this framework gave teams something relevant and involving right from the start and enabled them to proceed. 'Walking around the House' has become an important component of training and practice planning to deliver care planning. A typical comment from the stakeholder interviews was:

67 Year of Care.(2008). *Getting to Grips with the Year of Care: A Practical Guide*

“Getting some framework around what Year of Care looks like, getting the House, getting the menu... and having that common understanding of the key group, I think has been a great achievement.”

Stakeholder Report, Wave 1

Sharing results is promoted by the YOC programme as a practical manifestation of the changing relationship between the person with diabetes and the professional towards one of more equality. An exercise used during the training, highlights the anomalous position in the NHS whereby the individual often does not hold the personal information about themselves and their condition which they need to make self management decisions (Figure 9 below):

Figure 9: Discussing an unauthorised overdraft with your bank manger – how do you feel?

Imagine if your bank manager decided having your bank statements would cause you undue concern and he/she wanted to decide how you spent your money.

First role play: The person responds to a request to see their bank manger without knowing its purpose or having an up to date statement. The extent of their overdraft and implied criticism is a shock to them, they say little and it is unclear if they have taken on board the practical actions recommended by the manager. A six month review is stipulated.

Second role play: The person received their statement a couple of weeks before the appointment with an explanation of its purpose. They have looked it over, realise their spending is getting out of hand and identified some changes which would reduce this over six months. The manager agrees to send a six-month appointment if this doesn't seem to be working.

The participants reflects on:

- the power relationships this highlights
- the impact of not having the results on the meeting and its productivity
- the need for an effective self managing individual to have time to reflect, as an important element of decision making and behaviour change.

‘The Bank Manager Role Play’ from *Preparing your Practice for Care Planning Training (2010)*

The experiences gained from sharing results before the consultation provided immediate positive feedback for the practice team, motivating them to engage in the further work involved in reorganisation and change – it proved overwhelmingly positive for both professionals and people with diabetes:

“Since I’ve had my results, I’m more prepared and I know sort of what questions I need to ask, what I need to find back off them and it also gives me, erm, well it make it easier for me achieve my targets.

If the doctor just turns round and says to you ‘you’ve got high blood pressure, you’ve got high sugars’, there’s no information there. Because you’ve had that information, you’re talking about something you know about and not something you’re kept in the dark about.”

Person with diabetes, YOC training DVD

The following vignette (Figure 10) from the RCGP care planning document⁶⁸ illustrates the change in practice of one GP who implemented care planning in his practice:

Figure 10: Vignette

A GP in a small practice with very good diabetes outcomes agreed to switch to a care planning model because of the new provision of a well-funded enhanced service.

He was extremely sceptical about it however; he was concerned that giving patients the freedom to make choices about goals and actions would lead to deterioration in biomedical outcomes. Partly because of this concern he chose to do the care planning himself rather than delegate it to his practice nurse.

After further care planning training and six months of putting care planning into practice he was an enthusiast: the care planning encounter enabled him to explain to the patient their results, their risks and possible interventions. Equally, they were more able to share their beliefs and concerns. By the end of the pilot, his patients' biomedical results had improved still further. (London GP, 2009/10)

Once engaged in the new approach, the successes that people with diabetes reported helped to sustain the momentum. This is despite the additional workload created by administration of the system of appointments and information sent to patients. One GP reported that *"the workload has massively increased but we have absorbed it by staff morale"*.

Finally, the healthcare professionals' (HCP) positive personal experience allays any initial concerns that the process might engender anxiety in the individuals, leading to phone calls and more work. This issue was raised repeatedly in interviews and training by professionals and some people with diabetes. Tribal were unable to find much evidence that patients did get anxious, but this was a starting perception in some practices.

The limitations of a systematic approach without embracing the philosophy

During the second year, it became clear that the benefits of this systematic approach were only realised in the context of *HCPs committed to partnership working* (the right wall of the House). Without this commitment, the offer of an easy and practical action to staff, such as sending out test results prior to the consultation, was sometimes interpreted as an a relatively simple task to bolt on to previous ways of working and thinking. It did not automatically act as a support to better self management or change the experience of the person with diabetes if previously unhelpful habits continued side by side. Recognising that *the philosophy* was as important as *the structure* became fundamental to the definition of the YOC approach. This change in philosophy also needed to be communicated to and understood the by the non-clinical 'infrastructure' team so that all patient-facing functions were congruent with this philosophy (Figure 11).

68 Royal College of General Practitioners.(2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk

Figure 11: Philosophy of YOC

There is a danger that having a philosophy could be seen as 'woolly' or 'touchy feely'. It is quite the contrary: an agreed underlying philosophy is important as it is the motor that drives and determines our behaviour and motivations. For instance, if a practitioner believes that 'they are the expert' and the person with the LTC should 'do what they are told' they may behave very differently from a practitioner that believes that the person with diabetes is the expert in their life.

Philosophy is a critical, generally systematic approach which relies on rational argument and debate not 'motherhood and apple pie'.

The Year of Care philosophy was developed by a group of practitioners through debate and discussion and is summarised in *Getting to Grips with Year of Care; A Practical Guide* (2008).

Source: *Mind Your Language* (2010)⁶⁴

Where healthcare professionals had not embraced the concept of the person with diabetes as an equal partner nor understood their role as key actor in their own management, it seemed they could not respond positively to the individual's increasing involvement. They missed out on the positive experience for themselves and could not sustain the process within their teams. This was particularly obvious in the non-YOC sites that used *Getting to Grips with Year of Care* as a 'manual' without the training or the reflective learning sets the pilots had benefited from. The following examples from Tribal Consulting's *Interim Report* (2009)⁷⁰ represent practices where care planning was adopted without giving adequate consideration to the expectations and training needs of staff or the attitudinal shift in philosophy required to engage in care planning:

"The Year of Care can have the effect of slowing down processes because it focuses on patient priorities and they may only want to tackle one thing at a time."

Pharmacist

"We ask them if they've had a chance to look at the results we sent them. We threw it straight in the bin, we didn't realise. Some looked."

Practice nurse

"It's a lot of extra work. I have no solid conviction that getting bloods to them before is useful to them re getting more out of the consultation. I'm sure for some it will make a difference. Some are highly motivated people and will take the opportunity to analyse the results. Some will over-analyse them. Some will be empowered in that the doctor is taking it seriously, maybe I should. I'm not sure that enough people get benefit."

GP

In this practice, patients are not given a care plan.

"I'd find it irritating and patronising. There are lots of issues with setting goals. The principle is great but it takes a lot of time."

Tribal Consulting reported in their *Interim Report* that some practices did not appear to explain or include all staff in organisational changes. One practice reported:

69 Year of Care.(2010). *Mind Your Language: The Year of Care Consultation Skills and Philosophy Toolkit*. Available through the National Training & Support Programme

70 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the Year of Care for Diabetes: Project Interim Report*. November

“...it’s nothing like what you have been talking about. If you mention YOC to our practice nurse she will just not want to hear about it because our Year of Care has just been a big paper exercise – you send out all of these papers to people, they never fill them in and the consultation is a nightmare because it is spent completing the forms... I know there are things we can make better like improving some of the language and information on the letter we send out so we will do that and just continue.”

In one non-YOC area, they decided to send out results letters to patients without undertaking the team engagement and systems review processes included in the YOC approach. When one of the nurses was asked about using the results letter, her reply was – “*Oh no, we’re not doing that; it opens up too much of a can of worms.*” This comment reflects that when staff are not on board with the philosophy of the programme, important processes and practice are likely to be impacted or omitted.

One way to both promote and assess whether individual staff and the team as a whole have understood their new role to support self management is to address the issue of language, both spoken in the consultation and written on the materials given to or sent to people with diabetes. The YOC Programme became increasingly aware of this issue and produced a reflective guide *Mind Your Language: The Year of Care Consultation Skills and Philosophy Toolkit*⁷¹. This is used in training and includes exercises for a practice to work on together, including support to explore skills and identify areas for development and a questionnaire *Living with Your Diabetes and other Long Term Conditions Patient Survey*.

“Until you had a try, you don’t appreciate what you can achieve re the language you use with patients. It takes a lot to get that attitudinal shift.”

GP⁷²

“The questionnaire part of the results letter was good as it helped you think of questions. If I did have any questions I would be more prepared when I came in, if I saw something funny on the graph I could ask why.”

Person with diabetes⁷³

Figure 12: Mind Your Language, 2010⁶⁶

This is not about political correctness. The language used within consultations, and meetings between healthcare professionals and patients, is a key part of delivering person-centred care. The words and language you use reflect your values and philosophy – if you are not committed to working within the Year of Care philosophy and supporting self management, your language will reflect this.

The words you use and the way you frame and phrase things can have a dramatic effect on the person’s confidence and ability to manage their conditions, and therefore the effectiveness of your consultation.

71 Year of Care.(2010). *Mind Your Language: The Year of Care Consultation Skills and Philosophy Toolkit*. Available through the National Training & Support Programme

72 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the Year of Care for Diabetes: Project Interim Report*. November

73 Doherty Y, Ludbrook S, Turnbull R, Lewis-Barned N. (2011). *Diabetes Year of Care: The Key Drivers and Theoretical Basis for a Shift in Diabetes Care*

Conclusion

To achieve the changes within the NHS required to support people with long term conditions (LTCs) and, in particular, maximise the added 'value' self care can bring both for the individual and the wider NHS, requires changes in **attitudes** and changes in **practice** to occur together. A commitment to change by practitioners without the infrastructure that enables them to do so leads to demoralisation; the change in structure without attitudes is ineffective and potentially unsustainable. Either approach gives care planning, 'personalisation' and YOC a falsely bad reputation, and slows the development of practical innovation that is so desperately needed in this area.

Wider issues of culture and attitudes

There were two strongly held attitudes identified among some professional staff, which made it hard for them to recognise their new role in supported self management (SSM), and proved to be barriers to moving forward. Each is now addressed in the training programme.

“We do this already”

The issue of healthcare professional (HCP) roles in relation to SSM proved the bigger barrier, particularly for GPs who had been through years of training and become expert in 'a patient-centred approach'. But gaining greater understanding of what SSM entailed became a journey for everyone on the YOC programme. The teams eventually came to understand the challenge this posed to traditional ways of working for healthcare professionals; and to articulate that fundamentally LTCs are different.

The traditional role of the HCP has developed over the last century in the context of people with acute problems focusing on 'cure' or 'care', with the professional using their expertise to find solutions. In this traditional context, a patient-centred approach involves the professional eliciting the person's 'ideas, concerns and expectations', with a view to making a better plan for them.

Two of the principles from the YOC philosophy, codified in the Training Manual, address the difference for people with LTCs, including diabetes:

- They are in charge of their own lives and self-management of their diabetes, and are the primary decision makers and risk takers, about the actions they take in relation to their diabetes management.
- People are much more likely to undertake action in relation to the decisions they make themselves than decisions that are made for them.

These principles are new for many experienced healthcare professionals. Grasping and owning them is fundamental in enabling a clinical team to adopt the structure of care planning and the care planning House effectively, maximising the benefits for patients and staff alike.

Tribal reported in 2009 that those who stated that they had been doing YOC for years demonstrated a lack of understanding of what YOC entails. That is, not simply a set of component activities but rather an attitudinal shift affecting the power relationship of a clinician and patient. One GP articulated this attitude, as follows:

“I think it’s blown up out of all proportion. People who think that GPs need this amount of training for care planning don’t have an understanding of the range of things GPs need to keep up to date with. There are so many more things – like child protection – that I need to be up to date with in order to be able to practice. It’s not a good use of my time.”

GP, case study 2009

“Not suitable for ‘our patients’ who ‘lack motivation’; not our role”

The evaluation suggested that in some practices there was a significant gap between the philosophy and the reality and that some healthcare professionals felt that patients do not want to take on the responsibility of being a partner in their own care. Comments from some staff reflected attitudes that were not conducive to

delivering care planning in their practice. Often, practitioners were frustrated by patients who failed to follow their well-intentioned advice that was designed to improve outcomes and experienced the futility of their approach when people returned to clinic with no changes in their behaviour or biomedical outcomes.

There were also examples of stereotyping of groups from different socio-economic or cultural groups than their own, with poor understanding of what community and other resources people might have. A number of comments by practice staff during the first year of implementation represent the attitude amongst some staff that patients are unable or unwilling to be involved in aspects of care planning:

“It depends on their background. Some don’t turn up. Others will do all the work we’d hoped or expected... All the research suggests outcomes are better. But we can’t force anyone to be engaged. We can’t expect it from all our patients. In the USA patients see financial benefits, they see themselves as customers. If weight goes down, insurance premiums go down. On the NHS they see themselves as entitled demanders.”

GP

“When asked if they get patients to write the goals themselves, the nurse said, ‘They don’t think of concerns themselves.’”

Nurse

“We suggest goal setting and patients look blankly. The ideal world is designed around patients making all the decisions. In real clinical practice most patients don’t want that choice. They want to be told by me.”

GP

“Our role is to go through all the results – we have a lot to get through with them including alcohol consumption, depression, PALS, training, diet, impotence. At the end we ask them if there is anything they want to achieve but is often like pulling teeth to get anything out of them. You often find that you have set the goal for them.”

Practice nurse

These attitudes are addressed in the national training with positive results (Chapter 7). Feedback from healthcare professionals following the training is excellent. A sample of comments from training evaluation forms include:

“You have converted a cynic!”

“It’s made me reconsider my consultation skills and I will definitely change my practice to make it more patient-centred.”

Paradoxically, in the pilot site where training in behaviour change and motivational interviewing was commissioned early on in the YOC programme, it was ineffective and counterproductive. It seemed to reinforce the concept that the problem was within the patient rather than with the practitioner or the systems within which they worked.

In reality, these fundamental attitudes needed to be addressed **together with** the issues of the clinic infrastructure and the role of the HCP within it, and accompanied by a greater understanding of what living with a LTC entails. Only with all these elements present, could the issue of specialised support for people struggling to live with LTCs, and the need for specific motivational and coaching skills be addressed. And only when the whole system was engaged could this style of practice and support be introduced and sustained.

Practicalities

How many appointments?

The 'one stop shop', is a frequently described aspiration for people with diabetes and professionals alike. Two pilot practices saw YOC as a general opportunity to redesign services for the better, and introduced a one stop shop to deliver their diabetes services. The one stop shop is a restructuring of processes whereby a variety of healthcare professionals are available in one place at one time to screen, offer advice, and consult with patients.

When looked at through the traditional prism of a 'problem solving service', this has the obvious advantage of convenience and 'streamlining.' However, in terms of the philosophy of SSM, a two-visit approach is more conducive to reflection for the patient, with follow-up to support goals and action plans. For the person with diabetes, the time efficiencies are less beneficial when set against a longer process that supports them to understand their condition and coaches them in problem-solving skills that help in their day to day self management.

Ultimately, while the practices saw this way of working as the optimum, and it was popular with patients, it focused more on restructuring than recognising and implementing the core components of YOC. Nobody would say that improving the organisation of clinics is not important, but attending only to the mechanics of what happens, rather than the relationships, neither reflects the YOC approach nor appeared to improve outcomes or change patient experiences. Innovative ways need to be developed to give people access to a range of expertise whilst also paying attention to the need for a meaningful dialogue between people with diabetes and their healthcare professionals.

The two-visit process will have its own challenges, most obviously people not coming back for the second visit. These challenges can be overcome if patient sees the process as being useful to them and are working within a collaborative relationship with the HCP:

"I have a number of young men with diabetes who work away from home. They attend their screening but never come back to discuss any concerns with their diabetes. Since we have been care planning, I now send the results to them with an explanation of what they all mean. They now make an appointment when they come home and seem more engaged."

Practice nurse

The workforce: clarity about roles and objectives

The YOC programme had profound effects on the skill mix needed by practices to introduce care planning (see also Chapter 8). Tribal reported that there is a greater recognition on the part of healthcare professionals to the change in roles of GPs and nurses, and healthcare professionals appear to regard their roles as being clearer and more structured in terms of what they are required to do. Healthcare professionals spoke of greater responsibility (HCAs), of giving advice, options and choices (GPs), and of spending less time measuring heights and weights, and more time engaging with patients and allowing patients to take the lead (nurses). In Tower Hamlets, they discovered the central importance of the receptionist and administrators in explaining, engaging and encouraging patients to be involved in this new way of working. Tower Hamlets also had to train up the advocates who enabled their work with non-English speaking patients.⁷⁴

YOC also shone light on the workforce needs of people with LTCs across the NHS. Interpretation of the House turned out to be very specific to the local team involved in delivering care. The House provided a 'checklist' of issues, but needed to be applied appropriately to the roles of those providing services.

74 Tribal. (2011). *Diabetes Year of Care Evaluation Report*

The YOC programme coincided with a period when most PCT-led health communities were focussing on people with multiple LTCs, who are often frail and symptomatic with complex health and social needs, ie those who made most use of expensive unscheduled care beds. The national objective for everyone to have a care plan was an important element of the strategy to reduce these costs and emphasised the benefits of coordinating care within a patient-centred approach. Whilst people who are often described as being ‘at the top of the LTC – Kaiser Triangle’⁷⁵ represent the largest immediate call on NHS resources, a far greater number of people with LTCs were at earlier stages, receiving potentially preventative care in other parts of the NHS, mainly primary care. These were the focus of the YOC programme, as it was applied to diabetes.

The YOC training team recognised that the staff involved in caring for these two distinct patient groups worked in different settings, the community or at home rather than in structured primary care clinics. The practical interpretation of the care planning processes and the needs and expectations of staff attending training were very different.

The response of the training team was twofold:

- Firstly, they began to discuss these issues with sites prior to training, to ensure that people who could benefit attended. A pre-training site visit was organised to meet with senior members of any local steering group to agree common objectives.
- Secondly, a ‘workforce matrix’ was produced (Figure 13) which highlighted the different NHS settings in which people with LTCs are seen and the different roles of the various staff they meet.

The local model of diabetes care and care pathways

Just as it was important for the local organisation to understand the different places where people with LTCs received their care and their different day to day needs, so it was important within the local diabetes service that commissioners and providers were clear about where each person with diabetes received their annual surveillance review, and thus where the annual care planning review that would replace it would take place. In the pilot sites, this was a motivator to look at their whole system model. Without understanding this, they could not know which staff needed what competencies, and who should attend training.

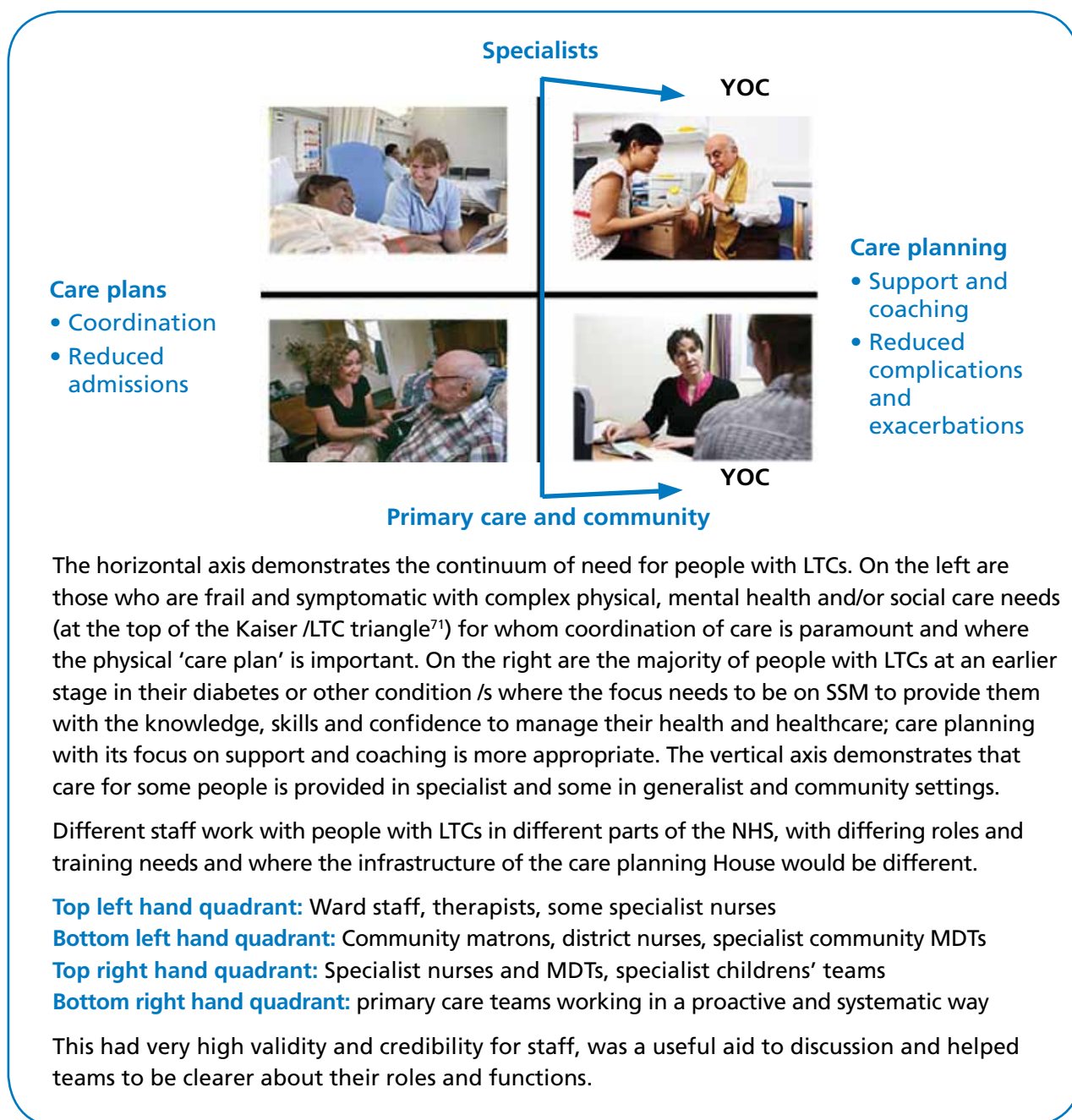
This proved to be the stumbling block in Calderdale. Despite much hard work locally, it has not been possible to extend care planning beyond the two pilot practices. In Kirklees, it was possible to scale it up across all practices thanks to clarity about their local pathways. At the same time, they have been able to make the financial savings outlined in Chapter 16.

In pre-training visits, many communities could not initially identify where the current annual review took place for each individual with diabetes. This became an important focus for discussion with a prospective new site, taking an average of nine months for the local diabetes community to ascertain, prior to training.

Figure 13 shows how YOC was developed for people on the right hand side of the matrix, who may have multiple conditions (diabetes, hypertension, renal and vascular disease, for instance) but who are attending primary care with the aim of SSM to prevent deterioration and long-term dependency. Local specialist teams who fulfil this role for some people with diabetes are welcome at joint training (Chapter 8 Table 6).

75 Department of Health. (2004). *Improving Chronic Disease Management*. (Online) Available from www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4075213.pdf

Figure 13: The YOC Workforce matrix (Appendix 6)



Leadership

The YOC Programme has seen outstanding examples of leadership in every site, and in all the successful early implementers. There are certain leadership roles which were found to be essential:

1. **Senior organisational leadership** including commissioning or ability to influence commissioning.
2. **Clinical leadership.** GP leadership is needed:
 - across the organisation
 - at practice level
 - during initial training.

76 Department of Health. (2004). *Improving Chronic Disease Management*. (Online) Available from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4075213.pdf

This must include someone with hands on experience of care planning or learning with the team. This provides a committed role model enabling those with a healthy scepticism to be a positive force for reflection, rather than a disruption.

“We have strong clinical leads...The medical director is very involved. We also have a lead GP who is very involved. This gives us more confidence that we have the right people round the table. The medical director attends patient events and goes out to the practices – this gives YOC a high profile at the practices.”

Project Board Member

3. Coordination/project management: this is often best associated with the management of the whole care pathway or service model and must include efficient administration and links to the clinical leader. A capacity to sort out problems, whether to do with IT, collection of data or identification of skills deficits, proved critical to success. Tribal reported that one local project manager had responsibility for several other projects, and that this created some challenges in delivery. They noted that ensuring central resources are available for coordination is important to the success of YOC.

4. Practice facilitation: The project recognised that many of the issues for people with diabetes about adopting new ways of living their lives, and the need to set their own goals and action plans, are equally challenging for staff:

“I can see the value. I’m not against the model or the idea. But there needed to be a lot more support on the ground level. Hold my hand, show me how it works. I’ve lost the plot. I still feel in melted phase and haven’t refrozen. This isn’t an established change in our practice at all. It’s not as if there isn’t the will.”

Practice nurse

One new site adopted a mentorship programme for practices post-training with great success. Detailed knowledge of and acceptability to primary care is a huge advantage. It was observed that a degree of emotional intelligence and a thorough understanding of the local community are crucial to success, in addition to generic project management skills. While these functions can be fulfilled by different people in different roles there is only limited transferability possible. Where the project manager was replaced by a coordinator rather than a facilitator (also with reduced hours) this led to active response from practices about the need for more support.

Issues of hierarchy and authority (personal and institutional) were also important. This meant that senior responsibility for delivery couldn’t be replaced by others’ motivation and enthusiasm alone. Some examples of factors that slowed the project include:

- lack of director or Board member who has a clear understanding of the nature of the project and can ensure it is a local priority
- lack of a lead GP prepared to take responsibility for implementation
- lack of a project manager with primary care experience
- lack of an interested GP to attend training.

However, an experienced facilitator/coordinator from one site, who had excellent skills and support from an experienced trainer, was able to compensate, in many ways, for the lack of a GP leader.

Change takes time

Embedding care planning for everyone will take time. For some healthcare professionals and people with diabetes alike, it seems to be what they have been waiting for:

“This has given me something to feel good about. I was planning to retire but have changed my mind.”

GP in non-pilot site

“Sometimes when you have done it before, things seem to get forced on you... whereas this way I prefer to discuss it myself... there’s more of a choice now, it’s my choice rather than someone else’s choice, that’s why I like it.”

Person with diabetes, immediately after first YOC clinic

People with diabetes not only need to be informed about change, they may need to experience the process over several cycles before they can engage with it really constructively. At the start, people with diabetes did not always recognise that something different was happening or their role within the new process. This was especially manifest in the aspect of receiving results before their appointment. Some patients interviewed in Year 2 reported that they felt more confident with their results when they received them the second time, and had a better understanding of what these meant. Tribal reported that *‘it will take some time for the impact of care planning to be recognised by patients’* (Tribal 2009).

By the final year, there was evidence that as patients became more familiar with the care planning process, they were able to gain greater benefit from the approach. Some said it helped them prepare questions for their care planning appointment. Others said that they had found it helpful to compare their results with results from the previous year and see how things had changed as a result of their action or lack of action over the previous 12 months.

“As part of the review of the new approach to care planning a GP described a patient who on the first occasion she received the letter containing the test results, she brought it unopened to the appointment as she thought it was for the GP. The second time she opened it and understood bits of it. The third time she had worked out what to do and had generated some ideas to discuss.”

GP⁷⁷

On the other hand, some patients interviewed in Year 2 were unable to recall whether they had received their results before their appointment.

Similarly, the new skills are complicated for practitioners, and to begin with traditional prescriptive approaches remained common. The organisational changes also took time to make and embed as they sometimes involved planned changes in skill mix and role, compounded by unplanned staff changes and unforeseen disruptions. But some practices reported their systems had become more efficient and it was more straightforward handling systems where patients already had an understanding of what to expect from previous appointments.

The PCRS-UK showed improvement over each year of three years in Tower Hamlets in the capacity of the practice to SSM. Learning a new skill slows clinicians down so there were many practical reasons why not everyone with diabetes was immediately involved in the care planning process. Kirklees acknowledged this in their Local Improvement Scheme (LIS) agreements, stipulating care planning with only 25% of people with diabetes in the first year.

Some healthcare professionals also emphasised the increase in knowledge and experience of diabetes that they now have as a result of the YOC and highlighted that this enables them to deliver a better service to patients.

In summary care planning, like any cultural change, is about the ‘long haul.’ The good news is that a great deal of the learning has been done. The YOC pilots were the ones that had to ‘learn by doing’, and whilst they can now confidently say that care planning can be embedded in routine practice (Chapter 9), this was only achieved as the pilot ran into its third year. Once the learning had been efficiently packaged in the quality-assured National Training and Support Programme, new sites still had to spend time reflecting on the philosophy and making practical changes to clinic infrastructure, but processes were accelerated. Kirklees has been able not only to roll out the programme to 83% of all their practices in one year, but also to spread this learning across the patch to the other healthcare communities working with people with diabetes. This provides a practical example of what can now be achieved.

77 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the ‘Year of Care for Diabetes’: Project Interim Report*. November

Chapter 6: Care planning – developing the support

This chapter has three separate components, supporting individual user involvement in care planning, IT and measuring care planning.

Key points

Care planning – the engaged and informed individual

- Engaging people in care planning involves a variety of methods beyond 'providing information'.
- These must be tailored for individuals, and local barriers must be actively identified and addressed.
- Extra resource may be needed for disadvantaged groups.
- Those with literacy, access or other issues may be doubly disadvantaged if they are not distinguishable in some way from more advantaged populations. Special means to identify their needs will be important.

IT and care planning

- Templates, codes and user manuals are now available to support care planning for the commonest electronic health record systems.
- Providing IT alone will not deliver care planning. Training and attention to attitudes, skills and systems are more important.
- However, appropriate IT available soon after training will speed up implementation and embedding.
- IT systems are essential to capture service use and unmet need for commissioning.

Measuring care planning

- Identifying appropriate metrics to assess impact and measure improvement is not straightforward.
- Data, evidence and metrics collected should be used to drive change and improvement.
- A Year of Care (YOC) Outcomes Framework is available to support self reflection, monitoring and improvement (Appendix 2).

Care planning – the engaged, informed individual

Engagement in self care, leading to better quality of life and health, is not only an outcome of care planning but also an essential ingredient of the care planning process itself (the left wall of the Care Planning House). Thus, preparing individuals to take part is a key responsibility of each clinical team as well as of the commissioners who support them. This chapter describes both activities which in real life support each other. The pilots developed a variety of mechanisms to do this, and a number of these have been incorporated into training resources. Useful mechanisms included:

- Information for individuals about service changes and the new approach in the appropriate medium and language.
- Involving healthcare assistants (HCAs), receptionists and administrative staff, who are often part of the local community and can provide reassurance about change and explanations.
- Practice-based information events.
- Links with wider community events (see Chapter 11) where practice staff attend.
- Sending out results before the care planning consultation is itself a powerful way to engage people, especially if they then meet staff who are receptive to building on their own ideas and agendas. The process of learning about engagement becomes a mutual one between 'patient' and 'healthcare professional (HCP)'.

For populations with poor health and language literacy:

- Culturally sensitive approaches:

“Most practices found telephone invites to be far more effective in terms of actually getting patients to attend – this enabled them to negotiate times suitable for the patient to attend, to understand if patients were abroad and to explain to patients what their appointment was for and how long it would last.”

London PCT

- Advocates from different cultural groups were included in national training in Tower Hamlets to ensure that they could support people through the process.
- Three out of eight practices set up group events to explain results and answer questions before the one to one consultation (see Chapter 11).
- Leaflets were produced.
- Test results were colour-coded to minimise literacy challenges:

All patients in Tower Hamlets are given a folder that has clear and precise information in colour which is comprehensible to all. This is used as the basis of all information given to patients and is an effective means of providing information to which patients can relate. A nurse commented on this aspect:

“Because we go through the blood results, they are more aware (because of the different colours) and therefore more keen to take the healthy options and book appointments to see if there is an improvement. Colours are an incentive. Everybody knows red is danger and green is good. Patients are more willing to come. They say – I’m coming back in three months.”

Practice nurse

These measures generated positive feedback:

“We had a meeting with all staff to change attitudes. We assume they (patients) just want to be told what to do, but that’s how the meet and greet came about. Let them come and tell us. It will be a slow change... It’s no good for people to complain. We need to get them to tell us what they want. We’ve asked

them to choose their best receptionist. Now the receptionists are on their best behaviour. I'm going to do it for the clinicians. We're supposed to be appraising ourselves. Who says if we're working well – it's the patients."

Nurse practitioner

Figure 14: Excerpt from Tower Hamlets case study, 2011

In Tower Hamlets, one of the practices has begun to hold two 'Preparation for Care Planning' sessions on alternate weeks. This is for people with diabetes who have recently had their biometric tests, and the purpose is to give them their results and prepare them for their care planning consultation.

There is a designated administrator who telephones patients to remind them about their appointments for biometrics, attending the group meeting to receive their results and prepare for their care planning appointment. At the meeting there is a brief presentation on things that can be done to help with diabetes and then patients are given their individual results letters. There is another brief presentation on understanding results and there is usually a doctor, nurse and HCA present to answer individual questions – questions are asked and answered individually and the whole group is not involved. There is a final brief presentation about the diabetes care plan. Patients have folders which contain a blank care plan and are encouraged to think about and tick any areas they wish to discuss at the care planning consultation. Patients are then given the date and time of their care planning appointment.

There is some initial indication that this approach has begun to **reduce the number of non-attendees** at the practice. Patients interviewed immediately after the session said that they felt that it **helped to build a relationship between the healthcare professionals and the patient** and that this would help them to feel more relaxed and encourage people to come for their appointments. They also emphasised that **they felt much better informed about their condition**, what the tests are for and what results mean.

Structured patient education

Diabetes leads the field of long term conditions (LTCs) in the availability of quality assured patient education programmes which meet NICE guidelines for Type 2 (DESMOND and X-PERT) and Type 1 (DAFNE) diabetes. These programmes have a strong evidence base for improved health beliefs, life style change and mood improvement, all key elements of becoming an engaged and informed patient.

The pilots were all involved in providing structured education before participating in YOC, Calderdale and Kirklees and North of Tyne had DESMOND, and Tower Hamlets used 'HAMLET', a local modification of the X-PERT Programme. It was expected that this would be systematically linked with care planning as an 'easy win'. DESMOND, in particular, is built on a similar philosophical approach based on providing support to people with diabetes to enhance their capacity and confidence to self manage, and ideas and resources are shared across the programmes. Taking the same approach to person centred care and using similar resources was expected to help increase familiarity for people returning to care planning in practice after the education programme. With limited capacity available, North of Tyne and Calderdale and Kirklees both increased provision of DESMOND during the pilot. However, it was difficult to link diabetes education systematically with care planning, which was being provided for the whole diabetes population because DESMOND was commissioned

largely for the newly diagnosed population. Thus, during the majority of the YOC pilot phase, people who had attended education made up a small proportion of those involved in care planning.

Since structured education and care planning are both part of the NICE Quality Standards recommended for everyone with diabetes, this is powerful argument for redesign of diabetes services to make sure that this occurs (Chapter 15).

The need for structured education has been strongly recognised in Tower Hamlets:

“When they started doing two-step annual reviews, it got patients really asking questions about their diabetes and demonstrated a huge lack of knowledge and health literacy amongst the immigrant Bengali population.”

London Stakeholder

A Project Board member spoke about the findings from the Picker Survey on patient education:

“Patients hadn’t been offered anything they recognised as education. They didn’t understand what blood tests were for even when they were told, they didn’t understand the implications of care, they were ignorant of risks, they were ignorant of what the medication was for and they were thirsty for more knowledge.”

Project Board member

While HAMLET was viewed positively, it was not well-attended prior to deliver of the YOC programme.

“I did the HAMLET course – it was very good and opened my eyes. It scared me – some of the people on the course were very heavy. For me, the course turned things around. I changed my food habits a lot. The course explained how to look after your body. It explained about the importance of eye tests and I get mine tested every year now.”

Person with diabetes

Considerable effort was put into understanding needs of the local population using social marketing techniques, with considerable benefit.

Figure 15: Excerpt from Tower Hamlets YOC case studies (2011)

A one hour taster session was also designed. Of those who attended the taster session, over 90% went on to do a full course. Everyone who attended any session received a DVD and workbook, which was available in three languages. During 2009, educational sessions were presented at 52 venues, during each day of the week, at various times, and in 18 different languages. In total, there were 9,940 attendances at educational interventions, reaching 6,640 individuals, comprising 60% of the diabetes population.

Support groups

The pilot sites were linked to local diabetes support groups. In Tower Hamlets, some people who had been involved in YOC wished to continue with this and a local arrangement has been set up.

Debating the issues

Throughout the project, there were a number of important debates within and across the programme about issues of engagement. The Tribal evaluation team were concerned that as a team, YOC had not penetrated the consciousness of patients. They reported at interim stage that there was some understanding of care planning, not in so many words, but in terms of the practical concepts of receiving blood results prior to appointments and being involved in setting goals. One researcher went so far as to challenge the team at Year 1 by saying:

“Patients will not be engaged in the process of care planning without an understanding of what it constitutes. The basic message with change management is to communicate and communicate effectively. Most patients do not evidence much knowledge of what Year of Care or care planning entails. They understand what processes they go through but are not able to contextualise it within a care planning framework. This is an omission that smacks of paternalism in that it implies we know what is best for you, we want you to be a true partner in it, but we are not really going to tell you what it is.”⁷⁸

People with diabetes sitting on local and central steering groups were strong advocates for change. They were also concerned that the project was not advertising YOC and care planning enough to local people. A differing view was expressed at the beginning, that it was not responsible to raise the expectations of people who were not attending care planning practices. The pace of change was frustrating for all. A key recommendation will now be that people with diabetes campaign for care planning to be available to themselves and others with diabetes, in the light of the positive learning from YOC and NICE recommendations.

A frequent topic of discussion when visiting non-YOC sites is the idea that not every patient wants to be involved in self management or care planning and people should have a choice. The view of the YOC Programme is that everyone is already self managing their condition and that care planning supports them to do this more effectively. That said, there is recognition that some people are more aware of and more confident with the idea. Offering options and choices is at the heart of collaborative care planning. One option must be ‘how much do you want to be involved in all this?’ and is in keeping with providing choice and consistent with the spirit of the NHS. As expressed by a nurse in North of Tyne: *“If I were a patient I would want to have a care planning system in place. I think it respects people more as individuals. It gives people more rights.”*

Information technology

The issues

IT and the changes needed to the Electronic Health Record (EHR), proved to be one of the major challenges, if not **the** major challenge for the YOC project.

The dilemma was that in an ideal world tested templates and coded fields would have been in place right from the start, since the project was based in primary care where many practices are paperless or almost so. However, as a developmental project it was not possible to predict what was needed until the second year and only then could the IT be developed to support it. Furthermore the best way to present results so that people with diabetes could reflect on them was only agreed after several rounds of training and agreement by the trainers. This dilemma was recognised by all, but none the less led to frustration.

While the lack of IT slowed care planning for a short while, its absence prevented the capturing of service use and unmet need from consultations for the duration of the project.

78 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the ‘Year of Care for Diabetes’: Project Interim Report*. November

“To be able to record where the gaps are in services; to be able to record what patients needs and wants are so that this can be fed back into the commissioning process. And, services can be provided, and that is not going to happen over night by any means, but that is key I think to making this all pull together and join up and work. I keep calling it the missing link.”⁷⁹

Different practices and pilot sites reacted to the absence of templates to support care planning in different ways. There were inadequacies in the use and capability of information technology across all sites. The difference, however, was in the response to these problems. Tribal reported that some *‘seem to use this as an excuse for not undertaking care planning to its optimum and not rolling it out extensively in a practice’* whilst others *‘recognise the issues but appear to work within the problems.’*⁸⁰

Where the level of commitment to care planning was high (the majority of practices), staff found a variety of innovative if cumbersome ways to use either paper systems or adapt electronic systems

“We have EMIS LV – it didn’t work well at the beginning but now it’s much better. The care planning document has been updated. We send out standard letters on the system and record goals which can be coded. If patients are referred to a programme, that is recorded on the system. The care plan is saved into the patients records.”

Nurse

Where practices were not engaged or enthused, lack of IT became the scapegoat. For some YOC had been seen as a ‘fix it’ to bolt onto current practice, with the view that filling in the template would deliver the outcomes. Not surprisingly, there was no more enthusiasm for care planning in those practices when templates did become available.

The critical learning for care planning is that collection of data for audit and commissioning is dependent on IT; but if the new culture and behaviours are to become embedded in routine clinical practice, the changes in healthcare professionals’ attitudes and skills must precede the introduction of new IT systems. IT then becomes an important enabler to sustain these.

The key components

Templates for care planning and specific fields and codes for data entry and robust call and recall mechanisms are required for the following reasons:

- to record the essential components of a care planning consultation as part of the routine clinical record
- to provide links to the administration of the care planning processes including sending out results letters; which may be provided from within the core administrative features of the particular system
- to enable reports and summaries to include this critical patient related information (for hand held records or transfer to electronic patient portals, such as Health Space)
- to reinforce training in this new approach to a consultation which is designed to support self management, but represents a significant culture and practical change for many clinicians?
- to provide aggregated data to support patient centred commissioning. Capture of referral data remains very challenging; there may be no READ code appropriate, especially with non-traditional providers, or there may be more than one provider of a particular coded service. Capturing some form of referral data is possible through free text which, although cumbersome, is useful for commissioners.

79 Sweeney G. (2009). *Year of Care Review Report*

80 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the ‘Year of Care for Diabetes’: Project Interim Report*. November

The YOC Programme went about addressing this in two phases, starting with the templates for the consultation and then moving on to support call and recall and letters administration when the ordering error became clear. In retrospect they should not have been separated.

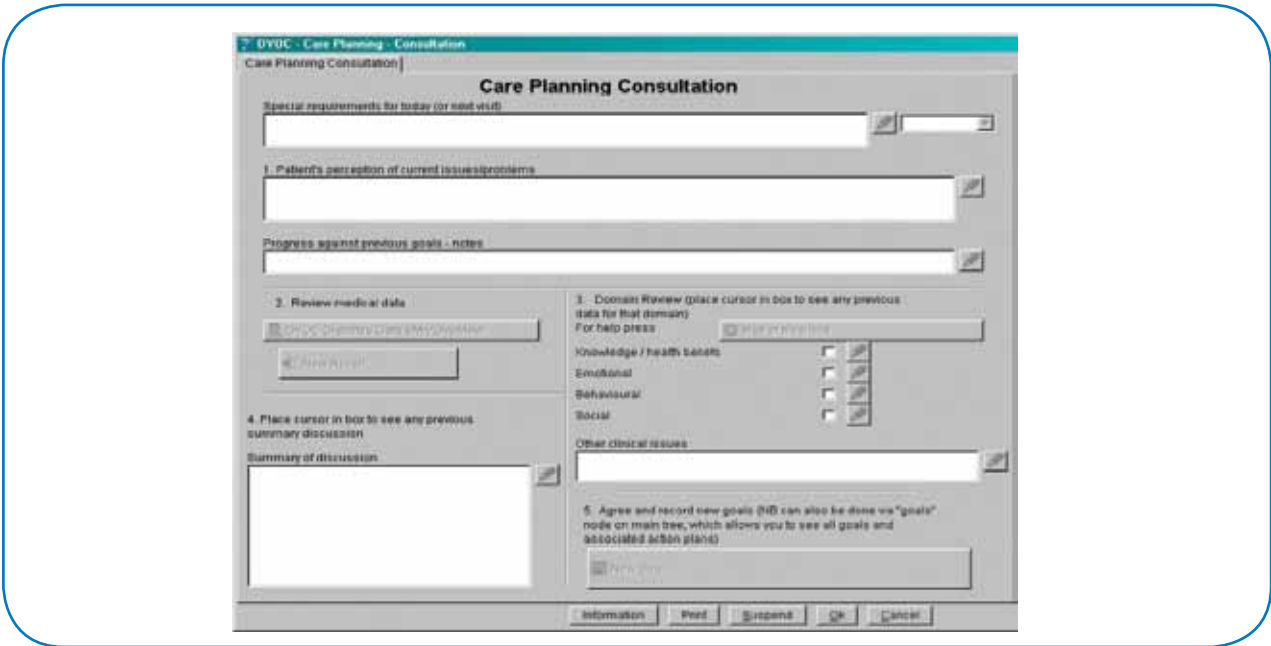
“So we got the care planning training in and done. We needed the template; if I did it again I would go with the full package. ‘Cause what we did was we taught, within the care planning training we taught the principles of care planning mainly around the consultation technique. What I would do if I did it again is I would have the whole package and that is the organisation of staff as well with the template. We would give practical advice on how to transfer information to pre-consultation letters and summary letters etc, but the timing was not right.”

Stakeholder interview, 2010⁸¹

To our knowledge, up to now, there has been no electronic health record in England which supports personalised care by providing fields and prompts to systematically record individual views, goals or actions that support self management of the individual with the LTC.

It therefore seemed important to address the issue of recording goals and action plans systematically during the consultation. With enormous support from NHS Yorkshire and Humber appropriate templates were developed using SystmOne as the test bed, which was already developing and piloting a complete diabetes record. These were introduced into practices in Kirklees when they became available. A sample of one of five simple templates is shown in Figure 16.

Figure 16: Template for care planning – SystmOne



However when this was offered to new sites as an early solution to their needs it rapidly became clear it did not address a key element of training, namely sending out results to people with diabetes in an appropriate format.

A second stage of work was needed to address this. This was identified, and supported financially by NHS Bexley. The team, which was one of the first to adopt care planning beyond the pilot sites, generously shared their experiences and local IT solutions with the YOC team. In a final stage transferability was tested in NHS Cumbria. Working with the project manager from Kirklees, they supported the writing of the final documents.

81 Tribal. (2011). *Diabetes Year of Care Evaluation Report*. (Survey of Stakeholder analysis reporting)

It is likely that if this aspect of the programme had been led from primary care early on, rather than the central team, the solution would have been in place a little earlier.

Achievements to date

- Available for new sites:
 - customer requirements for the Electronic Health Record to support care planning using the YOC approach
 - system by system instructions for new sites to configure their system to administer care planning.
- Key components of care planning including goals and action plans have been incorporated in the draft Diabetes Care Data Standard approved by the Information Standards Board available from www.ndis-england.org
- The key codes have been identified for submission for READ coding.
- Goals and action plans are being submitted for the first time from practices in Kirklees.

The future

Further work is needed by system suppliers to ensure that these elements are included seamlessly in their products so that the recording of goals and actions and issues of importance to the individual with a LTC became as routine part of the record as the traditional biomedical aspects.

There is a significant risk that the presence of the goal categories given by the IT system, which by definition have to be fixed, can subtly lead to a narrowing of goals and actions as actually desired by the patient.

For the first time it is possible to use this data to understand more about how this information might be used, whether within a practice or team, or collated for use in feedback, training or research. The potential to identify goals for living with diabetes extending beyond the purely biomedical is there, and more work is needed to see if this is helpful. Discussion with the YOC project has raised the issue of whether information which is still entered by or under the control of the HCP would in any case be meaningful and the prospect of patients not only being able to hold their own records but add their own goals, achievements and needs is attractive.

This work is being pioneered in Kirklees where a 10% sample of goals and action plans is shown in Figure 17.

Finally, more work is needed to enable the outcomes of referral or attendance at non-traditional community provider initiatives (Chapter 13) to be entered and recorded a part of the health record and this will be developed in the next phase of YOC in the North East.

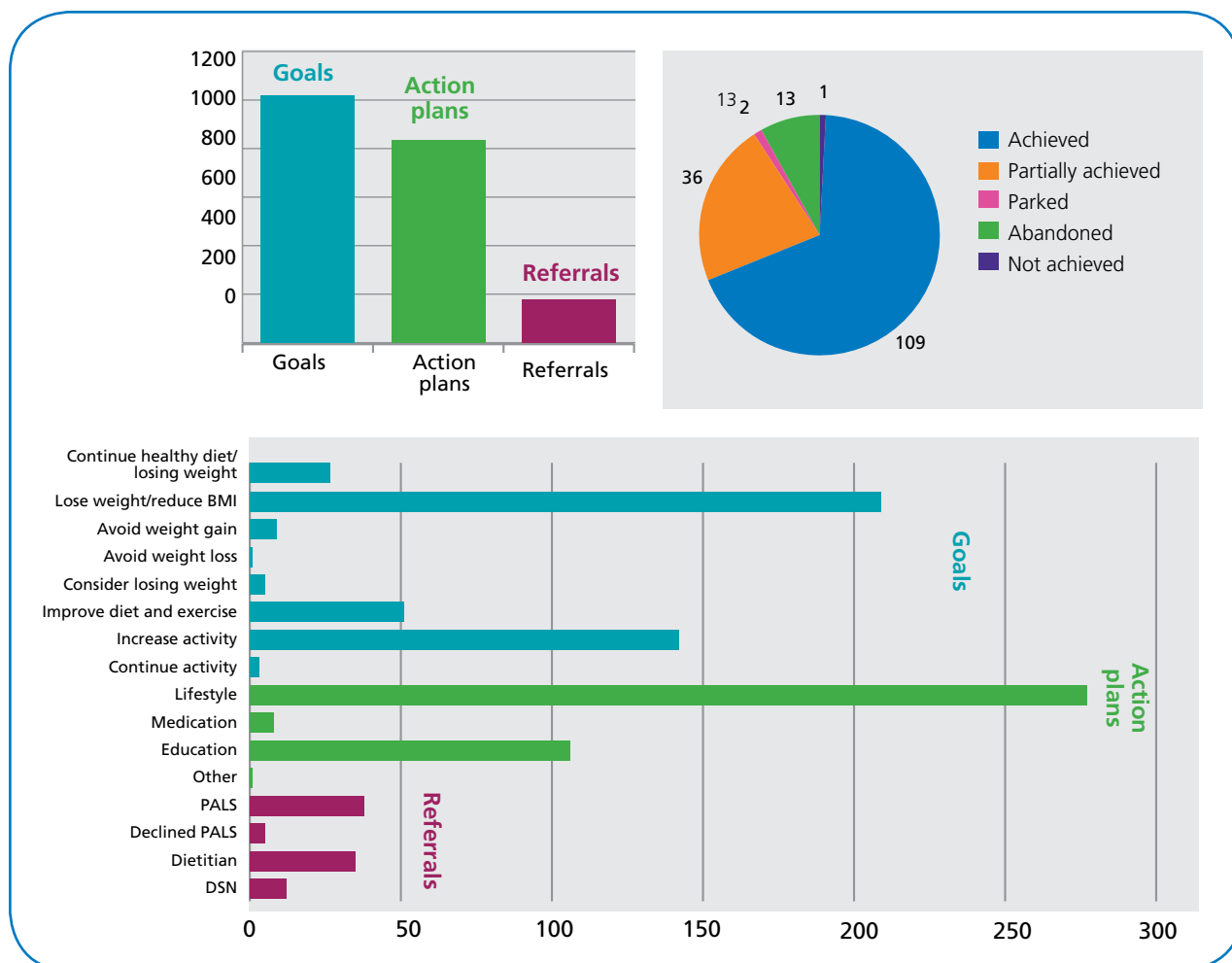
Measuring care planning

If care planning is to be embedded in routine care and new habits maintained, it will be important to identify metrics which can be used in everyday practice and enable everyone to see that they are doing a good job; this includes people with diabetes who will want to know the service they use is delivering best practice and be able to exert choice if necessary.

The material above indicates that this is not straightforward. Care planning has many component parts (summarised in the Care Planning House) all of which are important to achieve good outcomes. Some of these are not easily 'countable' or measurable routinely. YOC emphasises the importance of developing a 'learning' or 'reflecting' organisation in which routine data fields are set up to record what is important (as well as what is easy) to measure, and teams develop audit and evaluations 'frameworks' that suit their circumstances and address the particular issues they are reviewing.

Figure 17: Early data from Kirklees

The potential to understand more about patient goals, actions and preferences for commissioning, improvement and behavioural research



Top left: The goals, action plans and referrals of a 10% sample

Top right: The status of the goals at six months

Bottom: A breakdown of goals related to weight and exercise

Experience during the YOC Programme

The traditional evaluation which ran alongside the YOC pilot programme collected large volumes of questionnaire data on service availability, use and satisfaction, as well as experience of the clinical encounter and health status. However, at the end of the project, little of this was useful for assessing the feasibility and impact of the Programme.

We learned that such quantities of data cannot be collected routinely, as the volumes overload both the service users and the service itself. Each component also needs to be closely targeted on a particular feature of the care planning process that it is trying to assess.

Locally targeted collections proved far more useful to the sites, in terms of improving their structure, processes and immediate outcomes. For instance, interviewing staff and patients immediately after their care planning consultation about the experience of receiving their results gave an early indication of the usefulness of this step; and a facilitated discussion using the PCRS-UK tool enabled practices to reflect on their support for patients and on their internal processes, as well as seeing improvements year on year.

The best indicator would be patient feedback. Regularly sampling people with diabetes after the consultation proved difficult in practice. It clearly demands a high level of commitment from practitioners and patients, and more work is needed to see how this can be introduced once care planning becomes bedded down, and the organisational processes run smoothly.

Based on the care planning model, (Figure 8) the four aspects of interest were:

- What percentage of people with diabetes are sent their results before the visit?
- To what degree are people being supported or coached to develop their own goals and action plans, rather than have these prescribed?
- To what degree are these being recorded systematically in the records?
- To what degree is a summary of the consultation being made available to people after the consultation?

These aspects are all predicated on appropriate electronic health records being in place. The suitable templates only became available as the project ended but codes to record these aspects are being applied for and there is potential for them to be used in routine practice fairly soon.

Each pilot site developed slightly different approaches to commissioning care planning using Local Enhanced Service (LES) agreements, containing different indicators of the structure and process of care planning. Most stipulated key components of the 'practice pathway' expected, and one 'new non-pilot' care planning site has set up fields to record test results sent to patients as a proxy for receiving them. Two sites looked for the presence of patient goals and action plans within the routine record. Some stipulated that sample care plans should be submitted for peer or other review.

Working with other organisations

The RCGP practitioner's guide⁸² on how to implement care planning includes a comprehensive measurement framework and references to the many useful tools available to support all parts of the process. The function of these measures is to enable a practice to be able to answer the following questions supporting ongoing quality improvement:

- How will we know how we are doing and do it better?
- How can we improve our care planning skills?
- How successful is our practice at enabling people to self manage effectively?
- How can we monitor our attitudes and our processes?

New health communities working with the YOC training team regularly request metrics to use as they introduce care planning. To support them, the Programme has developed The **Year of Care Outcomes Framework** (Appendix 2). This is far from comprehensive, but includes the key components that the Programme identified as being important. It highlights (in red) examples of structure, service monitoring and outcomes from which a service could select, and which could be introduced relatively easily by a clinic or practice as they get going. It includes traditional biomedical outcomes with the caveat that improvements in these are only likely to occur once care planning has been established for 3–5 years. It is important to embed robust and sustainable processes, if the long-term clinical benefits that the evidence suggests are going to be achieved.

The YOC programme also contributed to the work at the Department of Health to develop a 'single' measure or set of PROMS that could be used to measure the quality of care for people with LTCs on a national basis. This work is continuing, but the Framework includes the potential national metrics which have been published.

A list with web links to specific tools, questionnaires and sample competency frameworks is provided as a web resource (www.diabetes.nhs.uk/year_of_care).

82 Royal College of General Practitioners. (2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk

Chapter 7: A National Training and Support Programme for Year of Care

This chapter describes, how and why training for care planning was developed to address the challenges identified in Chapter 5, how the additional learning from the roll-out to other non pilot sites led to a 'supportive' rather than 'stand alone' training model, and the impact of the training.

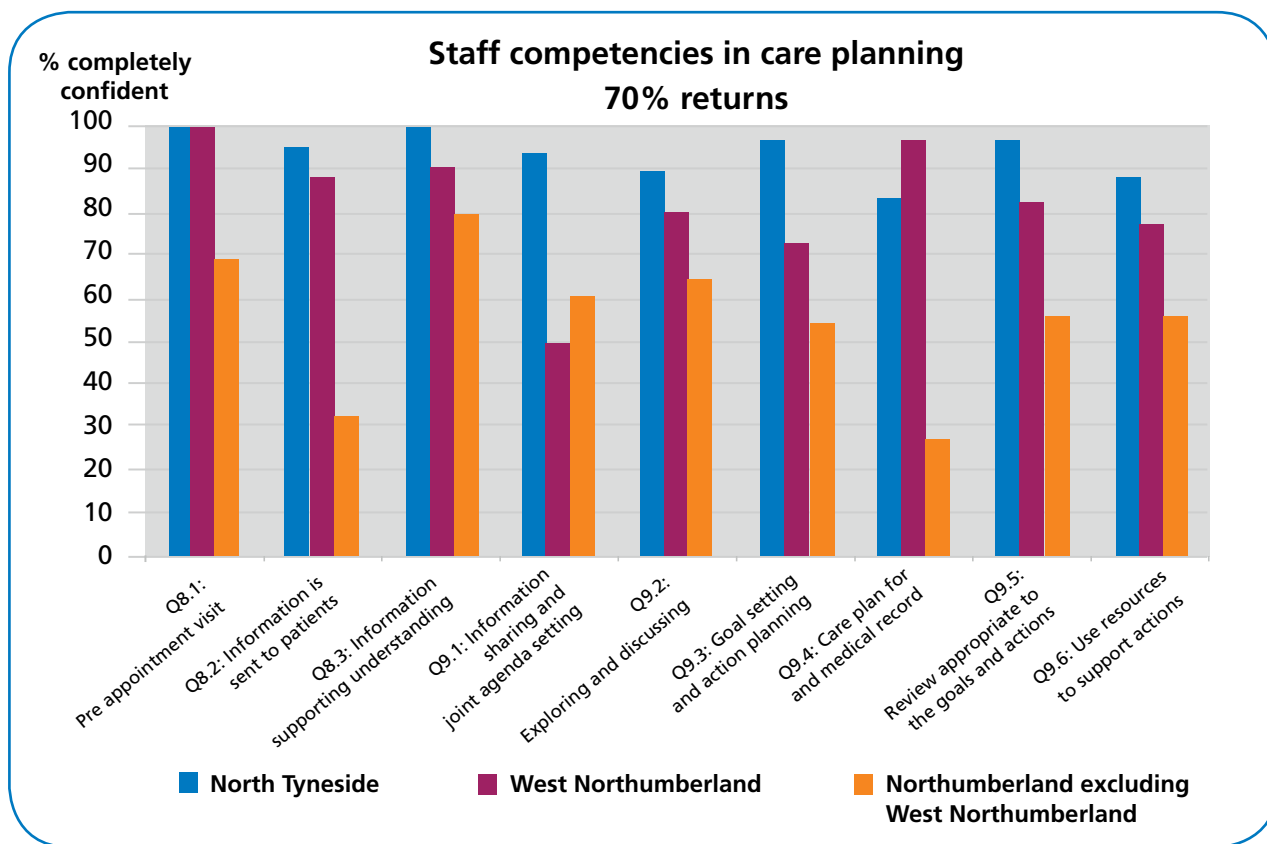
Key points

- There is a complete, tested training and support package to enable health communities to begin care planning with a flying start. This has been delivered to 1,000 healthcare professionals (HCPs).
- This programme addresses the essential issues of attitudes, skills and organisation of processes in a linked manner.
- The quality assured 'training the trainers' programme has delivered 40 trainers spread around England who are now training other staff within their own local health economies.
- The programme changes professional behaviour and is highly valued by those participating.
- The programme provides solutions to the challenges and dilemmas faced by healthcare professionals when working in partnership with people with diabetes to support self management identified in Chapter 5.
- New modules and a mentoring programme to support further development of clinical skills are in progress.

Developing the training

Training was seen as critical to the delivery of Year of Care (YOC) and care planning from the outset and each pilot developed their own solutions. Two sites commissioned separate organisations to provide training; both focussed on consultation skills (addressing the right wall of the House only), one specifically on motivational interviewing. North of Tyne utilised the training skills within their local steering group. They developed a bespoke curriculum specific to the structure of the care planning consultation, but also focused on attitudinal shift and organisational changes to all components of the House. This approach resulted in whole scale implementation of care planning in practices that attended. The effect of this training on a competency survey across practices North of Tyne which had (North Tyneside and West Northumberland) and had not (Northumberland, excluding the West) benefited from training is shown in Figure 18.

Figure 18: Percentage of staff reporting confidence in a range of competencies relevant to care planning for two areas which had received and one area which had not received care planning training from North of Tyne team



Legend for above Figure 18

- Q 8.1: Pre appointment visit
- Q 8.3: Information supporting understanding
- Q 9.1: Information sharing and joint agenda setting
- Q 9.2: Exploring and discussing
- Q 9.3: Goal setting and action planning
- Q 9.4: Care plan for patient and medical record
- Q 9.5: Review appropriate to the goals and actions
- Q 9.6: Use resources to support actions

In early 2009, NHS Diabetes commissioned and funded Northumbria Healthcare Trust to develop the North of Tyne model into a National Training Programme. This included changing the training from two half days to one and a half days, developing new resources and a ‘Train the Trainers’ programme to enable the YOC care planning approach to be rolled out across new health communities.

The programme was refined and improved in iterative rounds of training, feedback and reflection. Positive and practical solutions were incorporated into the training to help practitioners meet the challenges of care planning, such as those outlined in Chapter 5. Table 4 details how the training supports primary care teams to overcome the challenges described in Chapter 5.

Table 4: Training details to overcome challenges

Challenge	Training support activity
<p>Culture: The limitations of a systematic approach without embracing the philosophy</p>	<p>During training, the philosophy of YOC is openly debated using four statements from <i>Getting to Grips with the Year of Care: A Practical Guide</i> (Year of Care, 2008. p39). This allows participants to challenge each others' views and to see the common sense of adopting this philosophy for people with long term conditions (LTCs). The philosophy is introduced very early within the training to emphasise its fundamental importance in care planning.</p>
<p>Attitude: Not suitable for our patients who lack motivation; not our role</p>	<p>During the training session on philosophy, the statement <i>“Care planning needs to be available to all people with diabetes”</i> is introduced. The peer group always supports this statement and can be very adamant that it is for the person to decide if they wish to opt out of care planning and not the professional to make this decision on their behalf. In a later part of training, the use of scaling questions to assess importance and confidence encourages individuals to explore what might be making a difference to motivation, including specific strategies that show evidence of effectiveness.</p>
<p>Attitude: We do this already</p>	<p>By viewing DVDs of care planning consultations, participants are able to see what this approach looks like and how it differs from their own consultation style in terms of language and structure. This is one of the most powerful and highly-rated aspects of training, and brings about the ‘light bulb moment’ for many participants who believe they already do this.</p>
<p>Practicality: The appointment structure and roles within the practice</p>	<p>A specific activity is used to help develop an understanding of what needs to be in place to deliver care planning. It is made very clear in supporting information and during training that the whole system relies on a two-appointment process, best done by splitting out the ‘tasks’ associated with routine surveillance elements of diabetes care delivered by the healthcare assistant (HCA) role and the care planning itself. This enables not only the sharing of information prior to the consultation, but also that the care planning consultation is focused away from the computer and tasks which might get in the way of a dialogue between the two people in the room.</p>
<p>Practicality: The workforce – clarity about roles and objectives</p>	<p>During site visits, the concept of the ‘workforce matrix’ is introduced. This provides clarity on the differences between ‘care plans’ and ‘care planning,’ and also highlights that the focus of the training is primary care teams who would have previously delivered the ‘annual review,’ working with people to support self management. Where specialist services have been commissioned to deliver the annual review for people with Type 1 diabetes, joint training works well and helps to cement good relationships across the patch.</p>
<p>Practicality: The local model of diabetes care and care pathways</p>	<p>Each site is asked to describe its model of care, including where annual reviews took place. Once this is clearly articulated, including care pathways and models of care, the training team are then able to work with local teams to target training to those in need of it. In addition, further training modules and resources have been developed to target the competencies required for individuals who have a supporting role in care planning (eg HCAs, community nursing staff).</p>

Rolling out training – beyond the pilot sites

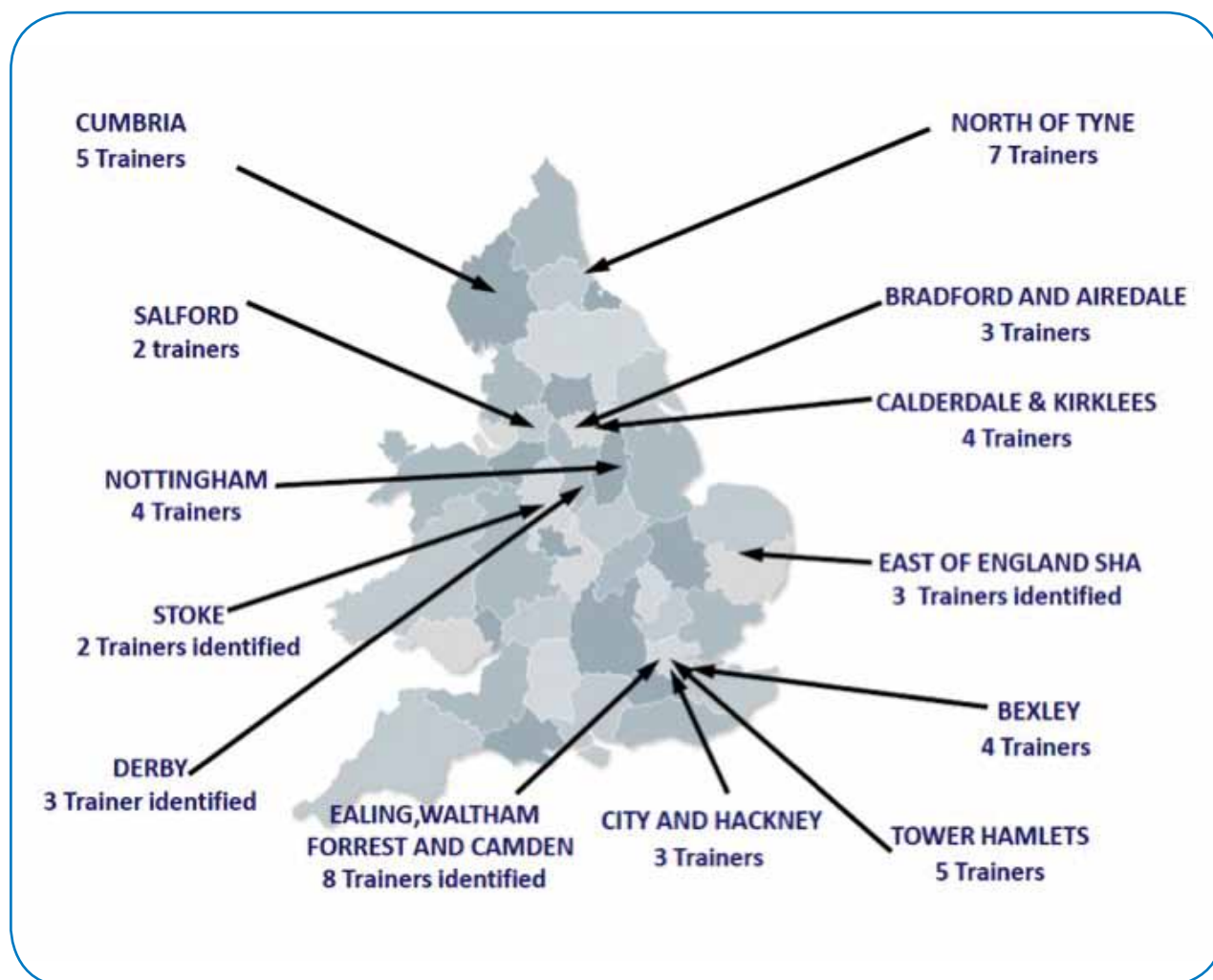
The programme steering group decided a quality assured 'Train the Trainers' programme would provide the most sustainable method of rolling out care planning across a health community at local and national level. The identification of potential trainers and a developmental programme based on quality assuring their delivery became incorporated into the overall programme and is outlined in Figure 19.

Figure 19: Criteria for quality assuring YOC approach



A great deal of interest has been shown in the YOC Programme, particularly in the subsidised training funded through NHS Diabetes. To date, 15 sites (including pilot sites) have received the national training (Figure 20) comprising approximately 1,000 HCPs and 40, soon to be 60 National Quality Assured Trainers. The training has also been tested in LTCs other than diabetes (Chapter 8).

Figure 20: Sites having received YOC training from the national training programme



The following **success factors** have been identified for new care planning communities:

- An initial dialogue to ensure a common understanding of the YOC and the expectations of the new sites, including clarity about the model of local diabetes care and what they hope to achieve from implementing the programme.
- YOC can help to drive service redesign. It fits poorly as a 'bolt on' to a traditional pathway.
- YOC implementation needs to be a substantial part of someone's job role, and a GP champion is crucial to gain credibility with local colleagues.
- It is important that the right people attend training:
 - at least one person (usually a GP), must have the authority to make organisational changes at practice level following training.
- When implementing this approach there is merit in focusing on a few practices and supporting them well.

These practices will serve as local exemplars of care planning, facilitating roll-out to the entire organisation.

- Practices needed support and facilitation to embed the approach – to set up IT and other systems, and identify ongoing needs for support. Incentives depend on local circumstances.
- Recognising the need to be explicit about the criteria for the selection of trainers; and the need for them to be credible with their general practice colleagues.

New sites had increasingly high expectations of what the training team could offer in addition to training. YOC is an iterative approach that evolves locally, and new issues arise frequently making the need for an ongoing support package important. Ability for sites to share experiences via a national collaborative network is under discussion.

The development of a support programme versus a stand alone training module

The YOC delivery and training teams worked increasingly closely together, learning something from each new health community. Thus, the training package became the hub for the Programme's learning and resources, and the support to enable health communities to implement care planning from scratch. The support materials provided are detailed in Table 5 and made available to all sites via a password-protected website once they have completed the three-day Train the Trainers programme.

Table 5: Support materials available through the National Care Planning Training Programme

Curriculum development

- Taster sessions – Preparing for Care Planning
 - Core Care Planning Training
 - Healthcare Assistant Training
 - Care Planning Awareness Raising
 - District Nurse Training in Care Planning
 - Train the Trainer and Quality Assurance Programme
 - LTC Care Planning Training (piloted)
 - Scoping and Identification of Extended Consultation Skills Training Requirements
-

Patient resource development

- Patient Materials eg sample letters, information about results, care plans, awareness raising materials
 - DVDs of awareness raising and consultation skills
-

Development of support materials for local steering groups to aid the implementation of care planning in practices

- Guidance Document – National Care Planning Training
- Coordinator/Steering Group Guidance Document
- Mind Your Language
- Practice Pack
- Evaluation Framework and Toolkit
- IT Guidance for Key Systems (EMIS, VISION, SystemOne)

The impact of training

The major success of training has been its effect on the attitudes of participants. Whilst it is unrealistic to think that all clinicians will sign up to the philosophy of care planning, there is generally a noticeable shift in the attitudes of the trainees which makes them want to go back and make the effort to change their organisation and consultation style (see comments below). It would be equally unrealistic to expect all individuals to become 100% competent in the use of these skills. However the training stimulates interest in the development of consultation skills, which for practice nurses, in particular, has not been a major focus of their pre- or post-qualification training. Feedback from healthcare professionals who have progressed to 'Train the Trainers' is indicative of the quality of and enthusiasm for the training.⁸³

"I have never attended such an excellent piece of training ever! This has really helped me focus on my role and think about the skills I need to do this."

"Having a peer review process has made me feel more confident that when I deliver the training that I am doing it justice."

"It's been a pleasure to deliver training that is so well thought out with really good quality resources – the DVDs are excellent."

Our experiences have shown that if all the conditions are right, that this training can make a real difference to the care that is delivered to people with diabetes, and the training and support materials and process have been carefully constructed, based on the learning from pilot sites, to maximise the potential for real change following training.

The future

As practices embrace the YOC philosophy, skills and practicalities, clinicians at all sites are asking for more help; despite being better informed, behaviour change for people with diabetes is hard. YOC facilitators and some of the quotes in this report show that moving from an exclusively biomedical approach is difficult and old habits persist. Tower Hamlets commissioned *Change Matters* (the Behaviour Change Training & Consultation Psychology Service from the local provider unit – now decommissioned due to financial pressures) to work with staff in a volunteer YOC practice identifying areas where staff would like more support and raising awareness of consultation skills and process for self-reflection. The YOC training programme is developing a mentoring programme to help identify and address further needs.

To close, a few quotes from feedback from the care planning training⁸³:

"Life changing training."

"I didn't think there was anything I could learn about consultation skills – but today I have definitely learned some new skills and I can't wait to try them out."

"This is something that should be offered everywhere."

Chapter 8: Care planning – the wider picture

This chapter looks at how care planning might be extended to people with other long term conditions (LTCs) beyond diabetes and to provide it in different settings other than general practice.

Key points

- The principles of care planning are transferable to other LTCs and can be used in other community and specialist settings.
- Practical details have been developed through testing the process of care planning for people with Chronic Obstructive Pulmonary Disease and those at high risk of cardiovascular disease (including diabetes) within delivery of the NHS Health Checks programme. Further development is ongoing for other cardiovascular conditions.
- The practical issues, and clinical challenges of care planning with people with multiple and complex LTCs remain great, but those testing delivery of the care planning process believe they will not be insoluble.
- When new health communities begin to adopt care planning it is helpful to start with something which has been tested like diabetes, even if the ultimate intention is to extend care planning to everyone with a LTC.

YOC as an exemplar for other LTCs

Clinicians who adopted the new approach to care planning found that it influenced their wider clinical practice with people with other conditions, and they began to consider how this could be developed to become the foundation of all their work with people with LTCs.

“Working in this way... has resulted in a shift with other patients... we have used the YOC as a template for other care packages.”

GP

Tribal reported one nurse saying that many of her patients had other LTCs in addition to their diabetes and that the care planning approach provided a valuable opportunity to discuss the patients’ needs in a holistic way, taking into account other conditions and personal circumstances. Another practitioner remarked, *“Care planning has made me look at patients differently. I focus less on the disease and take a more holistic perspective.”*⁸⁴

Working with different LTCs in different parts of the NHS

It is helpful, at this point, to re-visit the Workforce Matrix (Figure 21), introduced in Chapter 5 and Appendix 6 illustrating the different NHS settings in which care is delivered to people with LTCs.

84 Tower Hamlets. (2009). *Year of Care Case Study*

Figure 21: The YOC workforce matrix



Care planning for LTCs in a specialist context (Figure 21, top right)

Care planning had been successfully piloted by the specialist diabetes service working in North Tyneside and West Northumberland prior to the YOC Programme. The team wanted to be sure that the model and training could be introduced more widely. The programme is working with three specialist diabetes teams and the experience of one is described in Table 6.

Table 6: Vignette from Nottingham specialist diabetes service

The members of the consultant-led diabetes service at Nottingham City Hospital have a close working relationship with primary care, and initiated contacts with the Year of Care team. By the end of June 2011, about 50 doctors and nurses from primary and secondary care will have trained together, and Nottingham will have three trainers of their own to enable further courses to take place over the coming year.

The specialist service had a long-standing interest in support for self management, and they were ‘signed up’ to the YOC philosophy. After the training they took the practical model back to their specialist clinic in hospital outpatients. Working with clinic staff they determined how to send people their test results before the care planning appointment. They developed a short training course for the clinic healthcare assistants (HCA) which has also been attended by primary care staff. This has allowed the whole team to understand the philosophy. Within some practices, the HCA has been the driving force behind change and encouraging their GP and practice nurse to come on the training.

Staff have said, “it changes the consultation so that I do not do all the talking and I listen to what is being said”, “it is so much better for everyone”, “not sure why we have not been doing this already”, “I cannot ask open questions but I am learning to.”

People with diabetes have said, “it is really useful to know the results in advance, I used to get really nervous”, “you are listening to me”, “do you know what TEAM means? Together everyone achieves more – and we are working as a team.”

Nottingham have plans to continue to run courses, have an annual update about the consultation process and to embed what is taking place so that it becomes the norm.

This experience will be invaluable as other specialist teams respond to the new NICE National Quality Standard for diabetes, which includes care planning as one of the 13 Quality Standards (see Chapter 15).

Care planning in the 'community context' (Figure 21, bottom left)

People with LTCs make up the majority of those seen in community services, and also make up the greatest numbers of unscheduled admissions. They are usually symptomatic with multiple health and social care needs. Improving their care is a national priority. People with symptomatic chronic obstructive pulmonary disease (COPD) belong to this group. The YOC principles and structure were adapted for them as part of an integrated care pilot project in North Tyneside (Table 7).

Table 7: Vignette – Care planning for COPD in North Tyneside

A group of GPs has taken the principles of care planning in diabetes and adapted them for severe COPD. The two visits can be either at home or in the surgery. The district nurse (as key worker) carries out task-based measurements (eg peak flow rate, oximetry etc.) and provides basic information about the condition on the first visit. The second visit is the care planning consultation, where the person's self management plan is discussed, ideas and concerns about their illness are aired and rescue medication and inhaler management are put in place. Patients are encouraged to set their own goals and action plans which are recorded in the hand held record. There are links to a new pulmonary rehabilitation programme. A survey of the first 100 patients confirmed:

- 91% felt better able to manage their COPD
- 88% said they knew what to do when they got worse: 85% knew what medication to take, 87% were confident about taking rescue medication
- 50% said they now do things differently.
- **Resource use:** early data collections show
 - **Admission rates over 15 months: reduced by 50%**
0.66 admissions per pilot patients vs. 1.37 admissions per non-pilot patient with similar disease severity
 - **The A&E attendance: reduced by two thirds**
0.58 attendances per pilot patients compared with 1.83 attendances per non-pilot patient with similar disease severity

(The integrated care pilot in the Northeast (Integrated Care Organisation pilot site))

Extending care planning to other conditions in primary care (Figure 21, bottom right)

Over 50% of everyone with diabetes will also have another 'vascular' condition such as hypertension, coronary disease or renal disease, and these have been included in routine care planning (Table 9, Chapter 9). It made perfect sense for pilot sites to extend the principles of care planning either to people who already have heart disease or stroke, or to those who are at high risk of vascular disease as part of the Health Check programme.

Both Tower Hamlets and Kirklees are actively working on making systematic care planning routine for those with cardiovascular disease, recognising that whilst there will be small changes needed to the documentation and training, many of the same staff in primary care will be involved and skills will be transferable. North of Tyne has worked to develop the approach for 'health checks' (Table 8).

Table 8: Vignette – Care planning for health checks in North of Tyne

A North of Tyne health checks programme has adopted a care planning approach. Results and explanations are sent to patients following the check of their weight, smoking, blood pressure and cholesterol. At the care planning consultation, they discuss their goals. The clinician supports them to create a personal action plan. Master classes have been provided to support the healthcare professionals to work in this new way and discuss risk in a format which is understandable and attuned to the patient.

The team are also working hard to get this approach incorporated into the Local Enhanced Service (LES). The concepts of risk assessment and risk management fit well with the YOC two-step approach. (North East programme)

NHS North East care planning in LTCs pilots

Many people have more than one LTC. How can the care planning process help them too? A clinician in a care planning pilot noted that because of the way chronic disease management is currently set up, patients repeatedly visit the practice for different conditions, and that a more holistic appointment is more efficient: *“they could have seen somebody for COPD and then next week come back for diabetes and then a few weeks later for something else, so grouping them is actually very economical for the practice.”* (GP)⁸⁵

NHS North East established a pilot to directly address this issue. It was led by the NHS North East LTCs clinical innovation team and funded from the SHA Innovations funds as part of the *Good Ideas Investment Programme*.

Ten GP practices from across the North East formed a learning collaborative, supported by a programme manager. The YOC training team listened to the issues that emerged in early meetings and adapted and delivered a slightly modified one and half day training programme. The pilot included a formative evaluation, led by a team from Northumbria University, and including patient focus groups.

The Collaborative articulated the key learning from the YOC programme in the form of ‘**Anchor Points**’. These are:

- Articulate the distinction that care planning is different either from disease surveillance alone or traditional care provision; it needs specific systems to be in place and healthcare professionals to have specific skills.
- Each person should be offered a planned, proactive appointment to review current overall care and plan forwards.
- The person should be adequately prepared to enable them to participate in the consultation to the degree they wish.
- HCPs should strengthen the skills they need to work in partnership and provide self management support.
- Implementing care planning requires a whole system approach exemplified by the House model.

The participants were encouraged to start with non-diabetes conditions to test the feasibility of this approach. This meant that for the year they worked together, they mirrored the first year of the national YOC project. The group had to work out for themselves how to translate the anchor points into their chosen area. They had to do this without being part of a local initiative with the benefits of local leadership, commissioning or local facilitation within their home base.

It is therefore encouraging that by the end of the year, only one practice remained sceptical about the advantages beyond diabetes and all the others were actively implementing change.

85 NHS North East(2010). *Care Planning Learning Collaborative. Internal Evaluation*

Two practices had been part of the diabetes pilot North of Tyne and other practices chose to start with this. The consensus one year in was that it was probably best to start with diabetes because it is a well understood condition already handled in a systematic way in most practices, with tailored training available:

“I do wonder in the journey whether you have to go through the process in a disease-specific situation, to get the principles and the outline and the model sorted in your head and within your organisation, before you then try it out with other LTCs. I do wonder whether we’re taking a leap too far.”

GP⁸⁶

Implementing care planning in one tested condition provides a quicker way to understand the principle and experience the benefits before expanding to full or wider implementation.

Successes

- Care planning was tried out with other conditions, comprising:
 - people on disease-modifying drugs for arthritis who needed a holistic approach beyond simply drug monitoring
 - COPD
 - learning difficulties
 - multiple LTCs.

- The training programme was confirmed as the essential component.

“I think [the training] has made us think a lot more about the way we structure our appointments... I think already it’s had an influence on us listening more and asking open questions rather than just giving information which is what we’ve done in the past. I do feel we’ve always involved the patients but we have always taken the lead I suppose and now we’re maybe stepping back a little bit more than we were, and listening more.”

GP⁸⁶

- Practical solutions were found, for example:

“We gradually moved on to [be] less reliant on the results, and go for the no results approach... we use a different document *Making the Most Use of Your Appointment* leaflet to pick out things which is important for the patients.”

GP⁸⁶

- Processes are transferable:

“And the new sell to them is, because they might have all these different conditions, some of the management is very similar. It’s still collecting smoking data, blood pressure, kidney function... and so on, you see, so once you collect it once it applies to many other conditions.”

GP⁸⁶

- Overall contact time was not increased.

“What it was showing was that the appointments have got longer with diabetes... but the overall appointments, the amount of appointments have got less, so what’s happening is that I’m seeing them for longer appointments and dealing with small things so they’re needing to come back in to see GPs less.”

GP⁸⁶

Challenges

- The practical difficulties may be formidable. Included is how to make the documentation and the IT support the principles.

“We’re trying to plan it more generically so one of the things we’ve been doing is really try to get those tools, to get the communication right for patients, get the documentation right for health professionals to make sure that there’s a structure to the whole process as opposed to it being a little bit open ended and potentially wasteful.”

GP⁸⁶

- The clinical issues themselves are challenging

“Combining... long term conditions is really a challenge... The patient may have really complex medical conditions and they might not actually group quite nicely, so for example there are certain things group easily like diabetes and heart disease the more cardiovascular type of conditions. Then you will have something to do with respiratory. They’re slightly different the approaches. When you add on mental health and musculoskeletal conditions or neurological conditions, then it is very difficult.”

GP⁸⁶

- The workforce issues were complicated and will challenge practices to review who should be involved, how they should be trained and when and how this is determined.

“Most of the chronic disease management is managed by practice nurses but they are not managing a wide range of conditions, they’re only managing a certain type of condition such as COPD, asthma, diabetes, high blood pressure. So, if they have very little knowledge... certainly with neurological conditions so it will be very difficult.”

GP⁸⁶

- Better tools are needed for routine measurement to provide insight into current practice and clarify need for improvements.

“It’s how you define progress... you could do it very crudely and just measure the number of patients you’ve seen, but I don’t think that that would necessarily reflect what you’ve done with them or what the patients have managed to achieve themselves, so [assessing] content [would be a better way to measure] what’s actually going on.”

GP⁸⁶

Widening the debate: links with other national organisations

Royal College of General Practitioners (RCGP)

In 2009, the YOC national clinical lead and the clinical lead for Tower Hamlets joined a multidisciplinary working party within the RCGP to review what would be needed to introduce care planning for people with LTCs across primary care in England. Building on the work of the YOC programme and the evidence base for supported self management from The Health Foundation's Co-creating Health project⁸⁷, a report and recommendations were produced⁸⁸. These were endorsed by the RCGP College Council which has provided some funds for a clinical lead to develop a learning network of GPs to develop professional standards for care planning in general practice and incorporate them into undergraduate and postgraduate training.

Diabetes UK

In September 2009, Diabetes UK convened a workshop that brought together representatives from nine third sector organisations supporting and campaigning to improve the lives of, and the quality of care delivered to, people living with LTCs sharing learning from the YOC with this wider experience and expertise. Influencing change in the balance of power between patients and clinicians, and the need to influence service provision to help people self manage their conditions is a central tenet of all organisations attending.

The group explored some of the similarities and differences between LTCs, the challenge of shared language and the value of developing collaborative working. Participants developed their own action plan to take back to their organisations to begin to explore the overlap with the YOC. This work was crucial in helping to develop the 'workforce matrix' (Figure 13, Chapter 5) and in clarifying the differences between care plans and care planning.

NHS Diabetes

YOC has also worked closely throughout the project with NHS Diabetes, who also attended the meeting at Diabetes UK and is one of the key YOC funding partners. NHS Diabetes provided funds for the YOC Training and Support Programme and seconded one of the Regional Programme Managers to support this. The NHS Diabetes Regional Programme Managers have also had an important role in promoting YOC and supporting implementation of YOC within their regional areas. YOC has also used its learning from the pilot sites to help develop the NHS Diabetes commissioning frameworks for diagnosis and continuing care to support commissioning of diabetes services. The YOC web resource will continue to be hosted on the NHS Diabetes website.

The Health Foundation

The Health Foundation as a funding partner of YOC enabled the project to gather and share learning, supporting learning sets and conferences. The YOC project also made links with The Health Foundation's Co-creating Health⁸⁷ project sharing learning between the projects and have been jointly working with them to support a web based resource on SSM.

NHS Kidney Care

Following the Diabetes UK workshop (above), representatives from NHS Kidney Care, the partner organisation of NHS Diabetes have worked with the YOC training team to explore the benefits the approach might have for people either with early renal disease in primary care, or end stage disease in the care of the specialist renal team. Renal networks have been asked to apply to test how care planning principles apply to people with Chronic Kidney Disease attending specialist adult services and those being discharged to primary care, and how these can be embedded in practice.

87 Health Foundation. *Co-Creating Health Project*. (Online) Available from www.health.org.uk/areas-of-work/programmes/co-creating-health. Accessed 15 June 2011

88 Royal College of General Practitioners.(2011). *Care Planning – Improving the Lives of People with Long Term Conditions*. (Online) Available from www.rcgp.org.uk

Chapter 9: Care planning – what has been achieved?

This chapter describes the impact of care planning on patient and professional experience and behaviours, practice organisation and biomedical outcomes. It contains examples of what a new health community might expect to achieve if they adopt the approach.

Key points

- Collaborative care planning, using the Year of Care (YOC) approach, has been embedded into the routine care of people with diabetes across several health communities.
- Care planning is suitable for people from disadvantaged groups, including those with poor health and language literacy.
- Care planning improves:
 - patient experience and sense of control
 - patient behaviours
 - healthcare professional experience
 - healthcare professional behaviours
 - practice organisation to support self management (SSM)
 - practice productivity.
- Care planning is associated with:
 - improved biomedical outcomes across populations after 2–3 care planning cycles.

A: Care planning can be embedded in routine practice

By the end of the pilot phase, each site could report that a majority of practices in their health community were involved in care planning (Tower Hamlets = 97%, Kirklees = 83%, North Tyneside = 79% and West Northumberland = 73% Table 3 in Chapter 4). This is now considered 'the norm' for each community involved in the YOC Programme. (The exception is NHS Calderdale which disengaged from both the YOC Programme and the development of their diabetes services across the patch during the life span of the programme.)

Can these strongly held local assertions be verified? Based on the discussion in the previous chapters, it would be necessary to show:

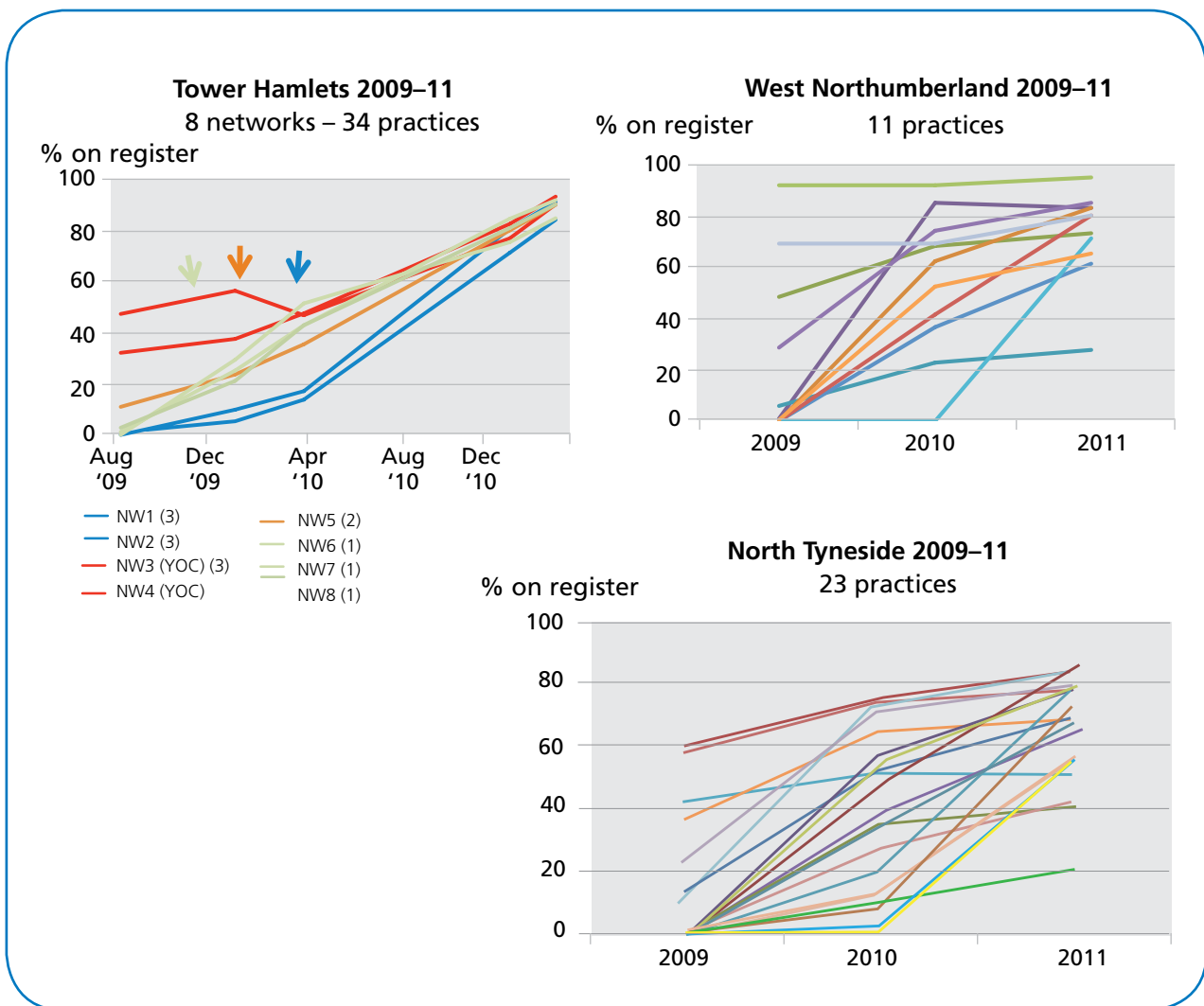
1. A 'process of care planning' taking place.
2. Test results were being sent to people with diabetes some days before the care planning consultation.
3. A change in the nature of the consultation towards one of collaboration and SSM.
4. Evidence of a written summary of the consultation (care plan).
5. Links to follow up.

With the exception of links to follow up, which has not yet been systematically recorded, the evidence for the implementation of care planning is described below.

1. A process of care planning

During the second year of the project each pilot became convinced of the benefits of care planning to their practices and populations, and began to reorganise their services, develop service agreements, monitoring and reporting arrangements. A small number of practices opted not to be involved. Data in this chapter refers to practices **opting in** to the care planning arrangements⁸⁹.

Figure 22: Percentage of people with diabetes involved in care planning consultations during the pilot collected from routine data collections (excluding Kirklees)



89 Kirklees data not yet available

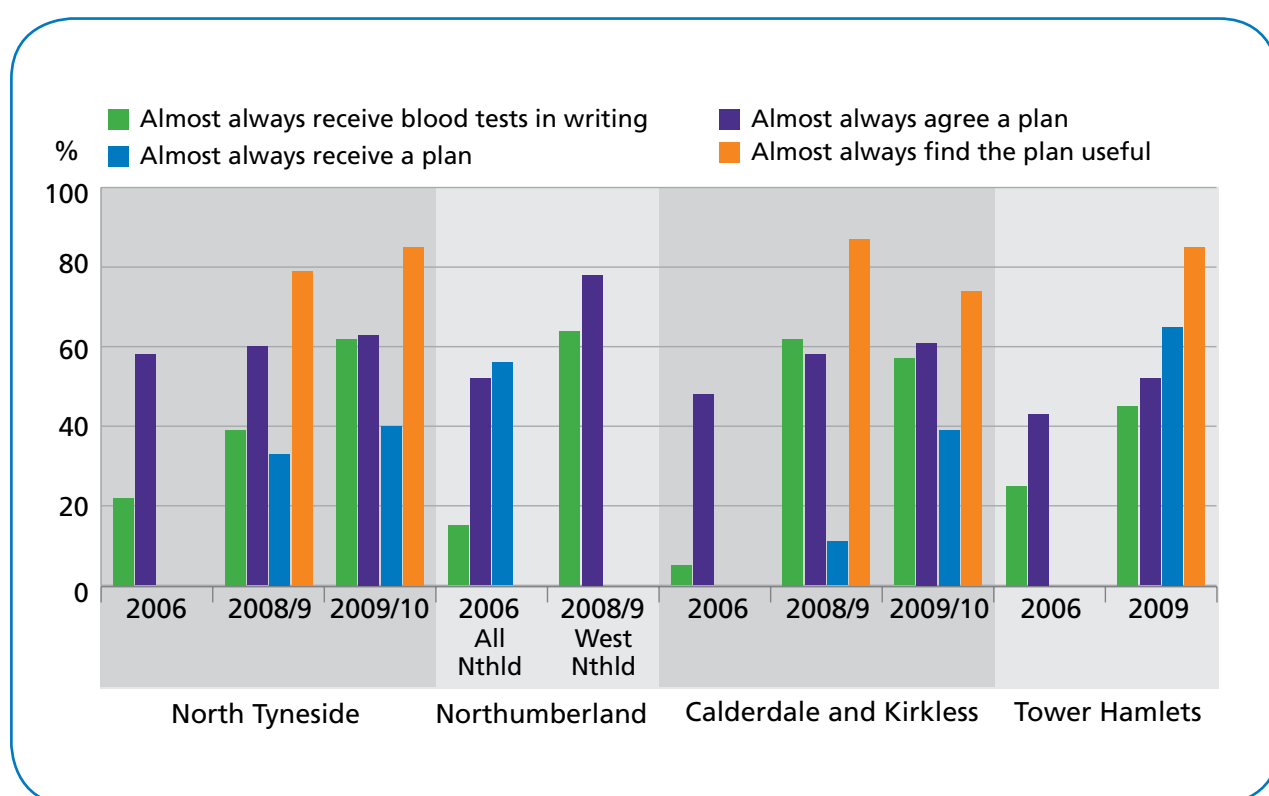
Taking part in care planning

Figure 22 demonstrates that while practices vary according to how fast they have been able to incorporate care planning into their routine work, by 2011 an average of 76% of people with Type 2 diabetes on the registers of practices involved in care planning were recorded as having a care planning consultation across Tower Hamlets and North of Tyne. The spread from YOC to non-YOC practices is best demonstrated by Tower Hamlets where YOC practices (networks 3 and 4, Figure 22) had a head start and were already including between 35% and 50% of their diabetes population by August 2009 when the practice was introduced more widely.

This trend is confirmed by people with diabetes themselves returning Tribal/Picker questionnaires demonstrating that more people were receiving their results in writing prior to the consultation and suggesting this was valued. The caveat for this data when used in this Report is that the wording of the questions was slightly different at each site, they were administered in different ways, at different time points in relation to the consultation and reflect the position at different points in the introduction of care planning between 2009 and August 2010 (Appendix 4).

It must also be born in mind that there were general improvements in diabetes services taking place between 2006 when the questions were asked as part of the Healthcare Commission (HCC) national survey⁹⁰ and 2008/2009 when the YOC project began to be implemented.

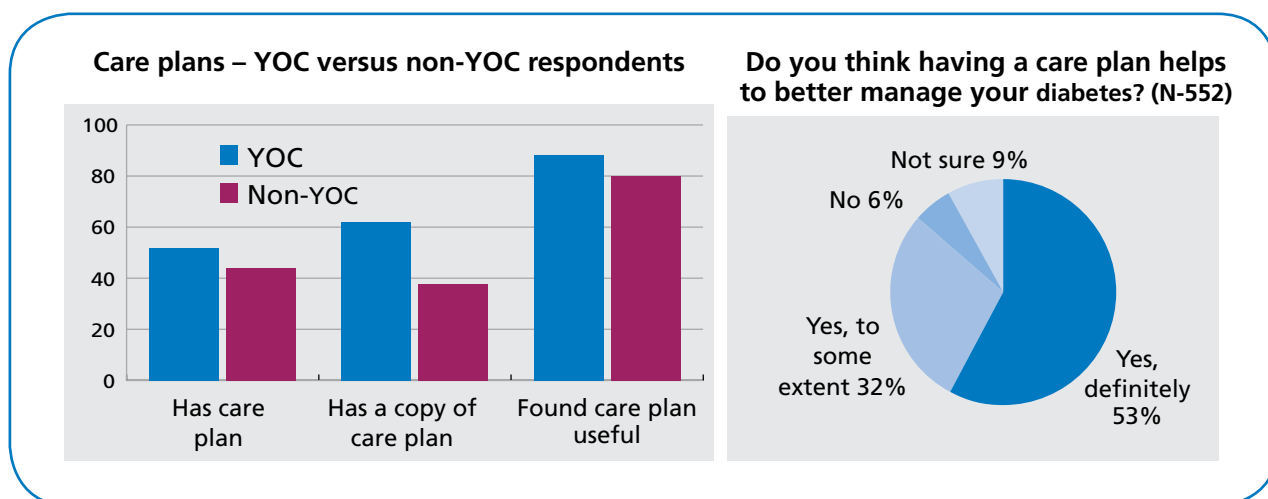
Figure 23: Changes in the care planning process reported by people with diabetes (Tribal/Picker surveys)



Between 2006 and 2010, a greater proportion of people with diabetes reported that they almost always agreed a plan to manage their diabetes increasing from 58% to 63% in North Tyneside (60% to 63% during the project) and from 48% to 61% in Calderdale and Kirklees (58% to 61% during the project) (Figure 23).

90 Healthcare Commission. (2006). *Diabetes: The Views of People with Diabetes. Key Finding from the 2006 Survey*

Figure 24: Tower Hamlets – agreeing a care plan in YOC and non-YOC practices using the Picker Survey (2009)



In Tower Hamlets (Figure 24) where only one collection was performed during the pilot, and neighbouring practices were already beginning to adopt care planning, the positive response increased from 43% to 52% for YOC practices, compared to 44% in non YOC practices. The highest results were obtained in West Northumberland where 78% of those asked reported they almost always agreed a plan.

Sending and receiving test results prior to the consultation

It is difficult to assess whether test results were sent prior to the consultation from practice reported data. Practice visits identified that sending out test results to people with diabetes to receive prior to the consultation did not always happen. This led to the clinical champion in Tower Hamlets reminding practices that this was mandatory aspect of the care planning process to receive payment within the Local Enhanced Service (LES).

Confirmation of this happening comes from patient reported data in interviews, focus groups and the questionnaires responses shown in Figure 23, and changes in the care planning process reported by people with diabetes (Appendix 4: Complete Data Tables) (recorded in late 2009 and early 2010). The increasingly positive answers to the question ‘almost always received written results in writing’ is the biggest overall change reported (Figure 23) with increases of 22% to 62% in North Tyneside, 15% to 64% in West Northumberland, 5% to 57% in Calderdale and Kirklees, and 25% to 45 % in Tower Hamlets. This is more impressive when it is realised that in 2006 individuals traditionally received their results **after** their clinic appointment, when decisions had been made, rather than **prior** to it. Figures also emphasise the gradual engagement for some people with diabetes who initially did not remember receiving them. However others were conscious of the change as demonstrated by the quotes below from two people with diabetes.

“It’s got better. It’s much easier to understand. It’s good to have a copy of your results so you can compare how things are going with the previous year.”

Person with diabetes

“I used to ask for results, but it is better to have it written down.”

Person with diabetes

Giving and receiving written care (summary) plans

Figure 23 also suggests there to have been a welcome increase in providing written care plans across all sites during the project (it was not an item in the 2006 HCC survey). Between the first and second Tribal collections those who reported receiving a plan rose from 33% to 40% in North of Tyne and 11% to 39% in the five practices submitting data in Calderdale and Kirklees. In Tower Hamlets, where there was only one data collection point, there was a considerable difference between those attending YOC (62%) and non-YOC (38%) practices.

Has there been a change in the nature of the consultation towards one of collaboration, SSM and improved engagement?

In 2009 Tribal reported that without observing consultation practices it was difficult to be certain that a patient centred, non-patronising, enabling and empowering consultation was taking place. We do have some evidence to suggest that this was the case. People with diabetes stated that they were happy with their consultations, that they found them useful, enlightening, that they had sufficient time, and went away in a better state than when they came and that they understand what they needed to do. Tribal⁹¹ noted that ‘understanding’ was a key word, one that was often mentioned by people with diabetes in all sites. Some still felt patronised and others simply wanted to be told what to do.

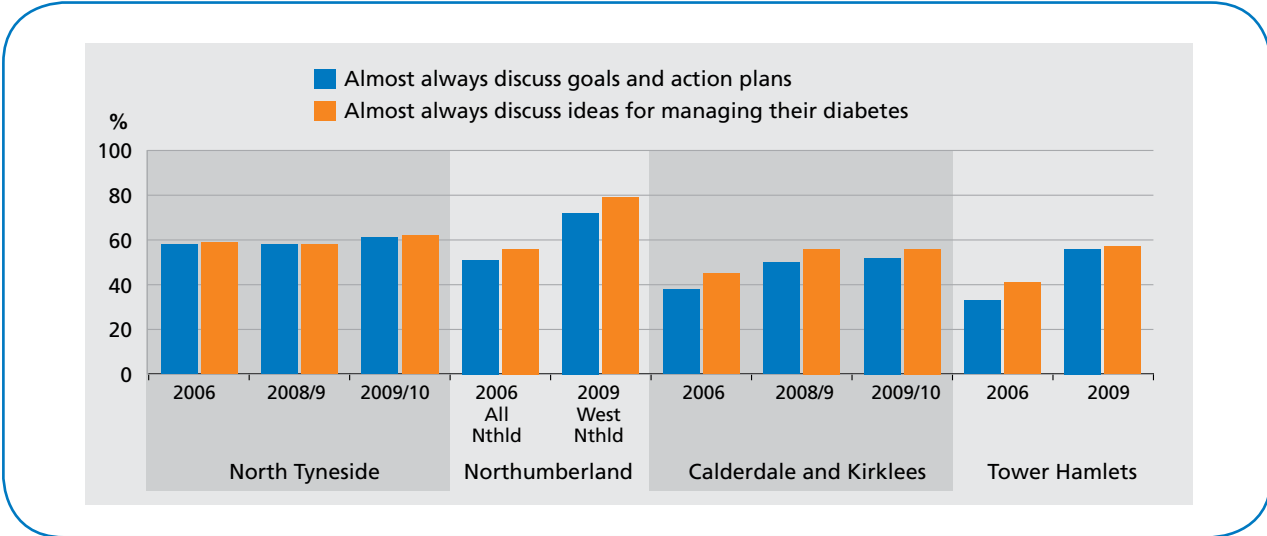
By 2010⁹² they were able to report that people with diabetes were becoming more engaged with their own diabetes care by going through the care planning process itself. This was also seen in greater attendances at clinics, responses within the consultation and goal setting, and actual changes in patients’ behaviours. Some people with diabetes articulated how setting their own goals helped them to take ownership of them and this made it easier for them to take action to manage their diabetes. The staff survey showed that many healthcare professionals at the pilot sites felt that patients were becoming better prepared for their consultations and had greater awareness and were more ‘empowered’. The survey also highlighted that engaging family members in the care planning process, especially where the person does not have English as a first language, can help to improve care planning outcomes.

These findings from Tribal interviews and focus groups^{91,92} across the two years emphasise that this new way of working takes time to embed. Not all clinicians have yet been able to embrace it; however the overall impression is that the nature of the consultation is not only improved from pre care planning days, but has gradually improved throughout the project.

Several tools were put in place with the intention of being able to judge the ‘quality’ of the consultations. Many practices found it difficult to administer the various questionnaire tools at different times after the consultation that and the poor returns for the CQI rendered these tools unusable. Therefore assessment can only be made indirectly.

At various times both Tower Hamlets and Kirklees included a review of the goals and action plans, as part of their monitoring arrangements (Chapter 6). However the programme concluded that the nature of these goals and the way they are currently recorded makes them more suitable for self reflection and peer review rather than performance management. The results of the survey data are shown in Figure 25.

Figure 25: Changes in the consultation reported by people with diabetes (Tribal/Picker surveys)



91 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the Year of Care for Diabetes: Project Interim Report*. November.

92 Tribal. (2011). *Diabetes Year of Care Evaluation Report (Survey and Stakeholder analysis reporting)*

Positive responses to the question 'almost always discuss goals and action plans' have increased from 57% to 72% in West Northumberland (WN), 32% to 52% in Calderdale and Kirklees (CK), 33% to 56% in Tower Hamlets (TH) and 58% to 61% in North Tyneside (NT). Figures for 'almost always discuss ideas for managing their diabetes' are 58% to 79% for WN, 45% to 56% for CK, 41% to 57% for TH, and 59% to 62% in NT respectively. The baseline for WN reflects the whole county and cannot be used for comparison, but the figures of 72% and 79% are impressive for these two questions despite the relatively elderly population. As might be expected change was greatest when the baseline was low. Where these questions were asked twice during the pilot phase there was a small improvement for both questions in NT (58% to 61% and 59% to 62% respectively) and to the first question (50% to 52%) but not the second question (56% to 56%) in CK. Tower Hamlets had no such comparator, but by 2009 had marginally exceeded both Calderdale and Kirklees collections. While encouraging, it is doubtful if such small changes are meaningful, and figures such as these cannot be used to draw causal inferences.

The importance of the care planning process itself in embedding new habits is emphasised by these observations from Tribal. The Year 1 interviews in 2009⁹³ observed:

"There is variety in the extent to which goal setting is undertaken by patients or by clinicians. In some cases, clinicians write the goals, while in a few practices these are done by the patients themselves. Sometimes the patients state the goals and the clinician writes them or types them in. Some goals were vague while others were more precise and specific."

However, by 2010, Tribal noted in their report,⁹⁴

"Some patients found goal setting easier once they were familiar with the concept from their initial experience and in some cases patients referred back to the goals between consultations."

"...some healthcare professionals described how goals had stayed with patients for the period between their care planning sessions and that they were able to reflect back on their goals and actions towards achieving them."

In terms of engagement with their care plan, a large percentage of people with diabetes reported finding this helpful in all sites. The histograms in Figures 23 and 24 shows that more people with diabetes attending YOC practices found it useful than those attending non-YOC practices in Tower Hamlets. In North Tyneside the percentage of people with diabetes finding it useful increased from 79% to 85% over the two years. This suggests engagement may have been increasing. In the five Calderdale and Kirklees practices, those finding it useful fell from 87% to 74%, perhaps reflecting the gradual disengagement of both these untrained practices and patients receiving their care from practices in this site.

In Tower Hamlets people with diabetes were asked about whether they were involved in making decisions about their own care as much as they would want to be in 2006 and 2009. Positive responses with people saying they were involved as much as they wanted to be increased from 56% to 82%. Furthermore 73% reported feeling that they were definitely listened to.

Satisfaction with the care planning process, as measured by the Diabetes Treatment Satisfaction Questionnaire (DTSQ) referred to in Chapter 3, in North of Tyne and Calderdale and Kirklees remained unchanged over the three years of the Programme.

Triangulating the information from all sources it is reasonable to conclude that care planning is embedded in routine practice in all sites with three quarters of all people with diabetes being involved in a care planning process, and this figure is increasing year on year. Consultations have become more collaborative with

93 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the 'Year of Care for Diabetes': Project Interim Report*. November

94 Tribal. (2011). *Diabetes Year of Care Evaluation Report*. (Survey of Stakeholder analysis reporting)

greater involvement by people with diabetes and this has gradually increased throughout the project with the exception of Calderdale and Kirklees pilot practices where the care planning model in its truest form, and training were not adopted. In the second phase of roll out to other Kirklees practices, following training and further practice support, the delivery of care planning is being assessed via the completion and inspection of records, in the absence of questionnaire data. There is evidence that plans are beginning to move away from a traditional biomedical approach to one centred on the individuals goals and priorities incorporating the necessary clinical aspects of care (Chapter 6).

Changes have been greatest where the baseline is low and the question of a ceiling effect should be considered. For instance not only have all sites requested further training in consultation skills to help those who find motivation and engagement most difficult, this may be needed before further improvement can be demonstrated.

The question of whether the changes in the value of the consultation through care planning is impacting on patients' behaviours and other outcomes is discussed in Sections B and C below.

B: Health inequalities – YOC and disadvantaged populations

The pilot sites were chosen because they included a spread of socio economic indicators particularly areas with significant diverse, Black, Asian and Minority Ethnic communities. There were strongly held concerns in year one that YOC might not be suitable for all. These were highlighted in the Stakeholder interviews at the end of the year.⁹⁵ Several questioned were concerned that the YOC Programme might have an unintended consequence of increasing inequality rather than increasing access to high quality and personalised care. There were concerns expressed that both professionals and people with diabetes might not want or be able to engage in the care planning process and change behaviours to meet the philosophy of YOC. This might risk re-enforcing existing health inequalities if people with diabetes did not develop the knowledge and skills needed to negotiate the care they needed: *"it could turn out to be a white middle class focused piece of work if we are not careful."* It was recognised that the relevance of these anxieties would only emerge as the project proceeded.

"How do we ensure that we have got equity across the patch, because we were saying, if not all patients may want to participate in their management in a care planning process, and we have never really discussed how we deal with that at a local level. Or whether we just adopt this approach and take everybody through it. So some of the learning that has to emerge over the next 18 months has got to be about well, you know, is this suitable for everybody or have primary care managed it for everybody, or what are the variances in the way that care is delivered."

"I think that this is a long term thing. If you are changing a whole culture, that is years of culture. And the results from that are not going to appear in two years; it will take longer. It could increase inequalities. I do believe that it can reduce them, because those people that it can potentially most benefit – if it is done right – would be those that aren't getting access to services currently because no one is informing them. So rather that the emphasis being on empowerment and self management, it could potentially also be a process to ensure access."

Over the next two years it emerged that not only could the YOC approach facilitate access, but the pilot site with the highest percentage of people from Black, Asian and Minority Ethnic communities improved the most. By the end of the third year there was a wealth of evidence that the approaches taken in Tower Hamlets had enabled people with Type 2 diabetes from the Bengali community to engage in their health and healthcare. Many of those interviewed said they felt they were more involved in their consultations and that being able to discuss things with the healthcare professional helped them to have more awareness of their condition and what they could do to improve their health. A person diagnosed with Type 2 diabetes in 2003 from Tower Hamlets commented saying *"YOC is a great idea because it is focussed around the individual. I'm happy that*

95 Sweeney G. (2009). *Year of Care Review Report*

I get more of a say in my care.” Participants at national training in Tower Hamlets in 2010 reported that for some Bengali women receiving a personal letter from her doctor and being required to present herself to discuss it in person was status enhancing within her family and helped engagement. Furthermore, a person with diabetes of Bengali origin said the goal setting process made it easier for her to manage her diabetes.

“Sometimes you need a push in the right direction. You can point out problems and there may be simple things you can try to help manage the problem.”

Person with diabetes from the Bengali community, Tower Hamlets Focus Group 2, 2010

This success did not come easily or automatically. The interventions to increase individual participation and address cultural differences and health and language literacy were described in *Getting to Grips with the Year of Care*.⁹⁶ Other examples are described in Chapter 6 and actions to involve the whole community in Chapter 11. Many of these required extra resources. When these issues were addressed engagement appeared high. This included participation in the Picker survey where although overall involvement was low, 50% of respondents were from the Bengali community.

A major concern must be for people with similar issues of literacy and understanding living in smaller communities within a large white population. Both North of Tyne and Calderdale and Kirklees have small communities of Chinese and South Asians. Those returning questionnaires in these two sites roughly reflected their background population.

Thus care planning has proved possible across very diverse populations including those with low literacy levels. YOC has shown that the extra resource needed to engage disadvantaged communities can really make a difference if targeted to support people to participate in their own care.

C: Care planning – what impact can you expect?

This section summarises the impact of care planning on individuals, healthcare professionals, the organisation of practices and populations. The wider impact of care planning and YOC on service redesign and commissioning is provided in Chapters 10, 15 and 16.

Chapter 5 describes how some people with diabetes and professionals can embrace the new way of working immediately whereas others may only be able to fully engage in the approach after they have experienced it for two to three years themselves.

This is the lens through which the impact of care planning over the duration of the YOC Programme must be viewed. It is illustrated by the accompanying case summary. This describes the experiences and outcomes in the only practice in England which has been carrying out care planning for more than 2–3 years (Table 9).

Patient experience and sense of control improves

At the end of the project Tribal⁹⁷ reported that it was clear the YOC Programme had a definite and dramatic impact on the lives of people with diabetes in Tower Hamlets.

Interviews in 2009⁹⁸ from North of Tyne and Tower Hamlets indicated that for some people with diabetes receiving test results prior to the consultation had an immediate positive effect on their experience of the clinical encounter.

“I could focus on the important things for me and get help.”

“Time to read (results) and think about what to raise... you know what was coming.”

**“It’s better now. There is more chance to see things and judge for yourself.
My family can look at the information – it’s helpful for them to understand.
Things are better... It is a lot better for me to understand these things.”**

96 Year of Care. (2008). *Getting to Grips with Year of Care. A Practical Guide*

97 Tribal. (2011). *Diabetes Year of Care Evaluation Report*. (Survey of Stakeholder analysis reporting)

98 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the ‘Year of Care for Diabetes’: Project Interim Report*. November

Table 9: Vignette – Care planning embedded in routine care

We began care planning with people with diabetes in 2005 by sending out test results before the practice diabetes clinic with an explanation.

We recognised the advantages straight away, and this is now considered 'normal care'. Our patients mostly can't remember the previous system. They expect to get their results prior to their visit, so that they have time to think about what they want to get out of their appointment. They are used to the techniques involved in the consultation and are prepared to construct their care plan. We've noticed that patients are better informed, our relationships with them feel better, and everyone in the practice enjoys doing the clinics more. Our clinics run to time more often as the process has become streamlined and everyone is prepared to take part.

While the experience was positive from the start, it took a while for the benefits to feed through. For instance Mrs R had up till then felt like a difficult person to help. She had hard to control BP, a high HbA1c, and a BMI which needed some improvement. She was on her 3rd year of care planning when she finally felt able to make the changes to her life that ultimately radically altered her profile. She saw that her HbA1c and BP were high again and she had put on more weight. She knew prior to the consultation that she would need to change. In the consultation, she discussed her options and resolved to have another go at the weight reduction. She came up with the idea of attending the gym, and a weight reduction class; the nurse was able to refer her to the healthy life scheme at the gym and signpost the local weight reduction classes. This was all reflected in the care plan, and this year Mrs R achieved her goal. By doing this she also managed to get a normal BP and HbA1c at target for the first time. She has continued to do well. It may have taken three years of care planning cycles but with the information she received, the education, the empowerment, the good relationships and the time, she got there.

As a practice we realised that this approach made sense for people with other long term conditions. Those with renal impairment who need tighter blood pressure control and had previously been seen separately had this included in their diabetes care planning discussion.

Our local prescribing advisor looked at our HbA1c results and drug spend for people with diabetes and compared us with colleagues across the locality. Out of 12 practices we had the cheapest drug spend, yet second best QOF score for glycaemia control, a pattern which continues. The practice with the slightly better score did so for 30% more cost. Our practice was using not only cheaper drugs, but fewer drugs.

We've also looked at all the biomedical data across our diabetes population. It is showing consistent and sustained improvement (see Figure 27). While there might be several factors at work, as a practice we are convinced that the emphasis on lifestyle that care planning brings has a large part to play in it. We are able to offer patients time to make informed decisions and come up with ways of helping themselves rather than reach for the prescription pad. So we won't be going back to the old pattern of care.

The Burn Brae general practice team: Hexham

People with diabetes also reported feeling more in control, not just in the consultation but in their daily lives.

“I know what is going on now which is a relief. I know what I need to do and what will happen if I don’t. I do feel more in charge both during the consultation and in managing my condition.”

“You have to do your own thing – they (clinicians) don’t necessarily know what is right for me as well as I do. You have to do what you have to do – not what they tell you to.”

“I am more in control. I have my results and information so I am not so reliant on the system. I can share the information with my own family and use it to encourage them to be more healthy.”

“It stops me from being so frightened about it. They explain all the side effects. I’m really happy.”

These positive changes were also recognised by the staff they worked with.

“...not only patient centred – also creates a sense of ownership having her results beforehand. Definitely helps people think about their diabetes and more efficient use of time.”

*GP following training*⁹⁹

Positive behaviour change for people with diabetes

Tribal were able to get a sense, as early as 2009, that people with diabetes were beginning to change, both in relation to their engagement with the health service and engagement with their own diabetes care through care planning. This was seen in greater attendances at clinics, responses within the consultation and goal setting, and actual changes in individuals’ behaviours. One Bengali woman set a goal to increase the number of days to go swimming – “it’s a good thing – has helped my illness – it was a suggestion but it was my decision.”¹⁰⁰ Others commented:

“I achieve a lot – I have become very conscious of what I eat and do more exercise. I started going to the gym to lose weight.”

“As a result... I walk more and have lost weight. I have also changed my diet.”

People with diabetes and healthcare professionals recognise that it may take several care planning visits before they are ready to make changes.

“Each time I get a greater understanding of my condition and understand more about how I can go about maintaining and improving it.”

Person with diabetes

“She was on her 3rd year of care planning when she finally felt able to make the changes to her life that ultimately radically altered the profile.”

GP – see Table 9

99 Year of Care (2009–2011). *National Care Planning Training and Support Training Evaluations and Feedback*
100 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the ‘Year of Care for Diabetes’: Project Interim Report*. November

Healthcare professional experiences improve

One of the most unexpected and welcome outcomes of the YOC Programme was the improved day to day experience for healthcare professionals, which for many began almost immediately after training¹⁰¹.

“It’s actually more rewarding. We don’t spend so much time doing heights, weights etc. We spend more time engaging with patients and finding out about their problems at home rather than ticking boxes.”

Nurse practitioner

“I enjoy doing the clinic a lot more now... working with them rather than at them.”

Practice nurse

“I’ve managed diabetes for 15 years – always hated it. But love doing it now. I get a buzz from doing the clinics – it’s no longer task orientated, tick box kind of consultation because the HCA has ticked all the boxes. I now do the stuff I want to do – I used to say the same kind of things in consultations but now every consultation is different. Less pressure on me – more a two way discussion.”

Practice nurse

“It’s absolutely 100% better for me and the patients.”

GP

In 2009, Tribal¹⁰² reported that practices were already getting the benefit of the changes they had made. They found their systems had become more efficient. It was more straightforward handling routines where patients already had an understanding of what to expect from previous appointments. A number of healthcare professionals emphasised the increase in knowledge and experience of diabetes gained from involvement in the YOC Programme and highlighted that this enabled them to deliver better care to people with diabetes. They reported seeing significant shifts in patient outcomes. By 2010¹⁰³ all respondents to the staff survey stated the YOC, care planning approach would be continued in their organisation after the pilot ends. Twenty-one out of 23 respondents would recommend the YOC/care planning approach to other colleagues.

Positive behaviour change for healthcare professionals

Healthcare professionals themselves report positive changes in their behaviours. Some of these resulted from changes in attitude leading to approaching their relationships with people with diabetes differently.

“Year of Care has made me look at my role as a practitioner – to take a step back and look at the way I deal with patients. It has legitimised me saying to patients – it’s all about you and your diabetes – you can use me as a resource.”

Practice nurse

“Year of Care emphasises the patient centred care approach.”

GP

“Working in this way... what they want to do and give them options and choices.”

GP

101 Year of Care (2009–2011). *National Care Planning Training and Support Training Evaluations and Feedback*

102 Tribal Consulting. (2009). *Evaluating the Delivery and Impact of the Year of Care for Diabetes: Project Interim Report*. November

103 Tribal. (2011). *Diabetes Year of Care Evaluation Report*. (Survey and Stakeholder analysis reporting)

“Care planning has made me look at patients differently... I have to invest more time... but it will get easier... as people get more used to it.”

Practice nurse

Many also described how they had become more systematic in what they do as well as more patient centred.

“Before followed a format with a checklist. Now consultations are more individual.”

Practice nurse

“Prior to Year of Care we were doing a diabetes clinic and following the model but not as strictly. Year of Care gives some discipline and structure to it... Year of Care allows me to sit down and give the pen to the patient to write down. I’m so used to writing it. But some patients give it back to me – oh no, I don’t want to care plan.”

GP

“Previously I was never, you must do this, you must do that. I always had a conversation and listened to their views. Now it’s more structured. I’m thinking more from the patient’s point of view, rather than the professional’s. It focuses your mind on their motivations to make changes.”

Practice nurse

Comments from people with diabetes indicate they recognised changes in the way that healthcare professionals were working. These changing attitudes were welcomed.

“The doctor asked about my priorities. He does focus on my agenda but he won’t let you get away with stuff. It was great, really good. A good mixture of professionalism and time.”

“It was good – I liked the way she explained the results. She said there was a number of ways of doing things. She listened to me. She respects that I have my own way of doing things. She presented things to me as ‘this is what you could do’ rather than telling me what to do.”

“He’s communicating more information than he did a couple of years ago. Last two occasions Dr... has been more open and able to communicate. Before he was more severe.”

People with diabetes also recognised and valued the structures and processes involved in care planning.

“The nurse did the review – it took about half an hour to 45 minutes which was enough time. We covered what I needed to cover – I like the way it is done and I think it is good the way they take you through the results. It is a two way thing – they go through the results, compare with last years and then ask what is important to me.”

“I prepared a care plan with the nurse. She saw the results and talked it through. I thought about the negatives and positives and how we could take things forward. There was an improvement after one week. She helped me identify what was important to me.”

Practice organisation to support self management improves

Delivering care planning meant practices had to change their systems (roof of the house). One of the most obvious changes is that the YOC approach to care planning offers people with diabetes a much longer appointment and through this gain more knowledge about their condition and the best ways for them to manage it. One professional said she felt giving patients a longer appointment was the most significant factor in improving outcomes. The overall reorganisation involved, meant that despite this increase in consultation length, the experience could be positive for the practice.

“My impression is we aren’t swamped as we used to be. The workload has eased because the number of interim reviews has gone down. It’s more manageable but we’ve needed strong admin to make it work. But we still don’t differentiate between easy and difficult consultations – everyone gets half an hour.”

GP¹⁰⁴

The organisational changes required, making sure that patients are called and recalled for annual reviews and follow-ups which had not been happening systematically in many practices prior to YOC, had a significant impact on administration.

“It made us look at the process and, dare I use those words ‘patient experience’. We looked logically at what we were doing and saw what we needed to do better. We devised care pathways with adequate administrative support.”

GP

There were also other benefits. Healthcare professionals spoke of real changes that had resulted in themselves or their practice. They spoke of being more of a team, of introducing changes into other LTCs, of having more meetings and communicating more and of greater satisfaction by patients with the attendant positivity emanating from that.

“Before Year of Care we hadn’t thought much about what needs to go on behind the scenes to make a clinical encounter effective and the practice nurse was struggling to do it all herself. The Year of Care house helped to clarify all the steps needed and gave us a framework to stand back and look at the service and to clarify roles and responsibilities so we now have far more robust organisational structures, better skill mix and better teamwork and communication.”

GP

These improvements in the practices’ support to people with diabetes and the organisation they put in place to support self management more widely were also demonstrated numerically via the PCRS-UK tool (See Chapter 3). Appendix 3 describes its use and shows changes in practice in Tower Hamlets and how the results can be linked to the key components of the House.

Practice productivity improves

While the improvement in quality of care was the prime aim of the YOC programme it is important to understand the costs involved. Within the practice the biggest cost is staff time and the longer consultation. The natural assumption would be that this would lead to increased costs. However this proved not to be the case.

“the new pathway is not only more patient centred but more efficient in time for both patients and healthcare professionals.”

Practice team member

Figure 26 demonstrates that overall care planning is cost neutral because of the changes to skill mix it promotes. Using the care pathway approach demonstrated here, detailed costs of clinical and administrative staff were obtained from a sample of practices in all pilot sites, before and after care planning was introduced. Whether a practice benefits financially or not from making the changes required for care planning will depend on their previous efficiency and working arrangements. In two of the practices the GP chose to be involved when care planning was introduced, in addition to the practice nurse who had previously seen a majority of people for their annual review, because of their interest in this way of working. This led to increased costs being recorded using this methodology but the difference between a nurse and GP based approach are shown in Figure 26. No two practices are alike as demonstrated by the histogram, and by the examples of changes in individual practice costs.

Figure 26: Costs associated with delivering routine care in primary care before and after YOC



There are other costs to be considered such as contacting patients and producing resources. Clearly in some practices these could be absorbed within the efficacy savings. In the future these issues will need to be resolved as part of national or local commissioning arrangements (Chapter 14).

These costs do not include the enormous amount of extra work each practice had to do to change the way they worked. The high uptake of care planning and the intention to maintain it after the project was over, suggests that the advantages outweighed the burden. One GP commented on this balance saying “the workload has massively increased but we have absorbed it by staff morale.”¹⁰⁵

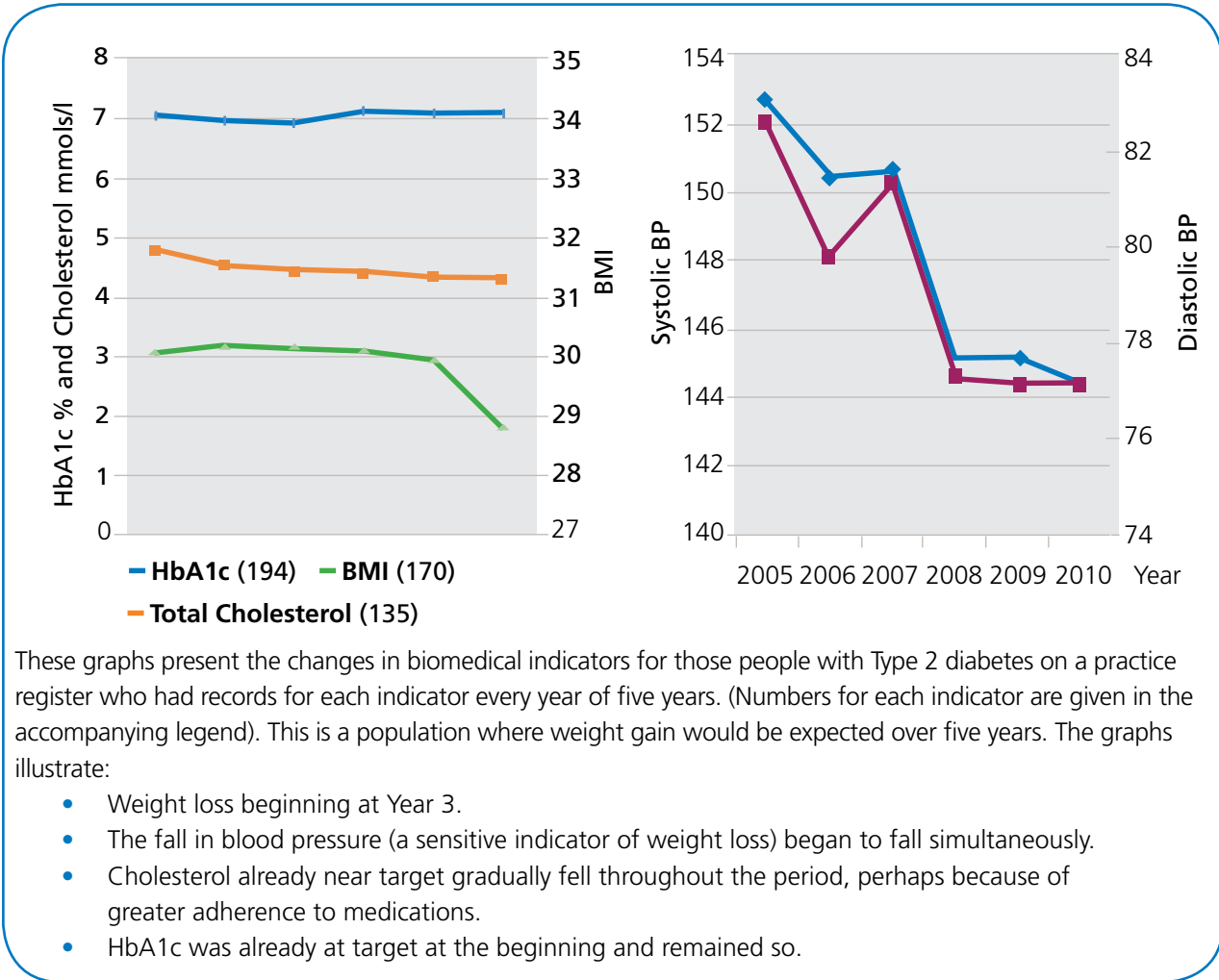
At the start of the YOC Programme it was expected to be able to show changes in terms of use of resources across the local health community. While the tools designed proved unequal to the task, in reality care planning only became routine at the end of the project and too soon to show any changes in use of hospital resources. IT systems proved inadequate to record the total use of practice time throughout the year. Anecdotally people seemed to be coming back less often in some practices as quoted above. In Tower Hamlets the introduction of packages of care with recommended recall intervals for different groups of patients was in tension with a care planning approach of identifying the best follow up arrangements with each individual.

Biomedical outcomes improve across populations

While change occurs at different rates for different individuals the experience overall is that it will take three to five years before measurable change in biomedical markers will be seen at population level, and even longer for reductions in the major complications in diabetes.

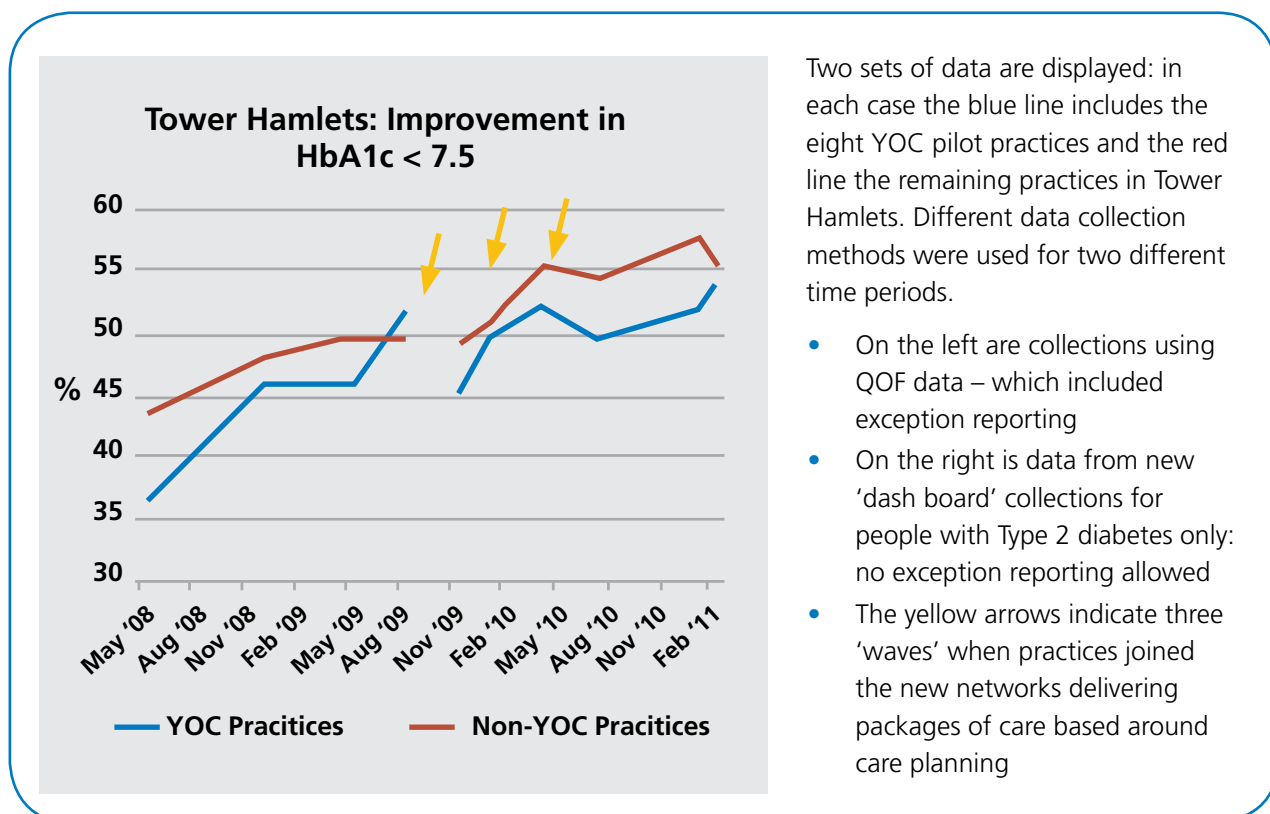
Figure 27 shows results for Burn Brae (referenced in Table 9), the only practice in England carrying out care planning for five years. It shows that the improvements expected from a care planning approach are possible using data from approximately 200 middle aged people with Type 2 diabetes.

Figure 27: Changes in traditional biomedical indicators in diabetes care following the introduction of care planning. Burn Brae practice (see Table 9)



These excellent figures are derived from an affluent population in a northern market town. However YOC also appears to show improvement within disadvantaged populations. Many other things were happening simultaneously in Tower Hamlets when the HbA1c results displayed in Figure 28 were obtained. A causal relationship between the reductions of poor HbA1c results shown here, with the introduction of YOC is not being proposed. However, clinicians sometimes question whether attention to the individuals' goals rather than to biomedical targets may result in deterioration of clinical outcomes and the potential of poorer QOF points. This is a false assumption and seems unlikely in practice from these interim measurements.

Figure 28: Tower Hamlets: the percentage of people with a HbA1c < 7.5 in various groups during the YOC pilot project.



Looking at the impact of care planning overall when using the YOC approach, the Programme has demonstrated great improvements in the experience of receiving care for people with diabetes. It has also shown that healthcare professionals prefer working in this way. Involvement in the care planning process itself leads to people having a greater sense of control over their health and healthcare which they value. For some the benefits are immediate but for many this is a gradual process involving two or more care planning cycles before healthier behaviours are adopted. The limited data suggests this influences improvements in the important biomedical indicators of diabetes health in a way that can be sustained, so the long term burden of the devastating complications of diabetes may be reduced for both people with diabetes and the NHS.

Chapter 10: Year of Care and commissioning

This chapter provides an overview of how the pilot sites went about the commissioning tasks that arose during the project and guides the reader to the subsequent chapters which contain the detail.

Key points

- Commissioning for Year of Care (YOC) and diabetes has to be seen in the context of the local commissioning strategy and tasks for people with long term conditions (LTCs) because of the many overlaps and links between the components and the needs of people with diabetes and those with other LTCs.
- While no single framework (comparable to the House framework for care planning) can be recommended YOC has described the key commissioning components and provides practical advice on what works well and how to go about it.

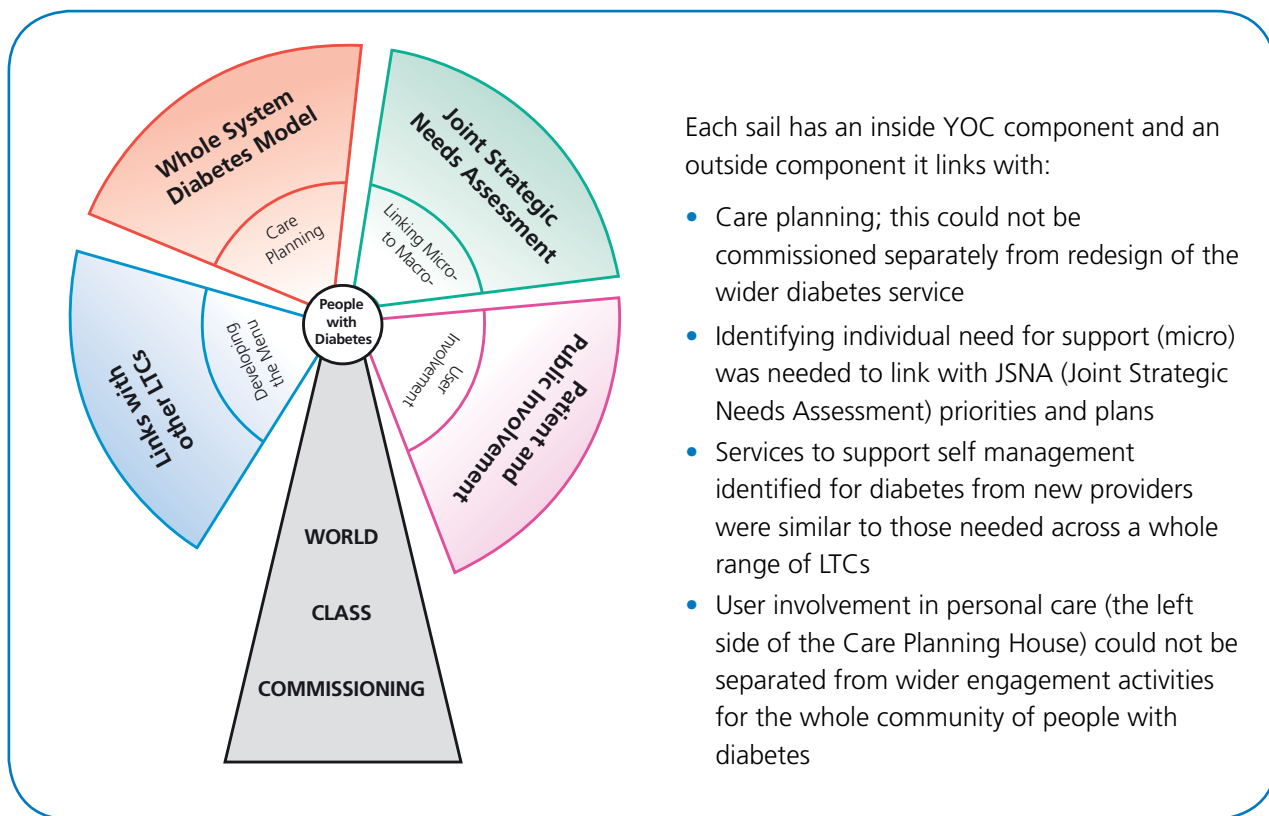
The YOC model (Chapter 2) seeks to ensure that appropriate local services are commissioned to support the choices people make with their healthcare professionals during care planning, to support self management and to achieve and maintain good health and wellbeing.

The pilot sites initially identified four specific commissioning tasks to support the YOC Programme:

1. Commissioning care planning.
2. Developing the menu of local options.
3. Linking micro-level to macro-level commissioning.
4. Service user involvement.

As work progressed during the first year they found that these specific elements linked to the wider work they were undertaking across their local organisations. Commissioning for the YOC thus became a highly complex endeavour with many component parts. As with care planning, pilots found it was more manageable if broken down into a set of linked tasks and work areas, which were represented as the sails of a windmill (Figure 29).

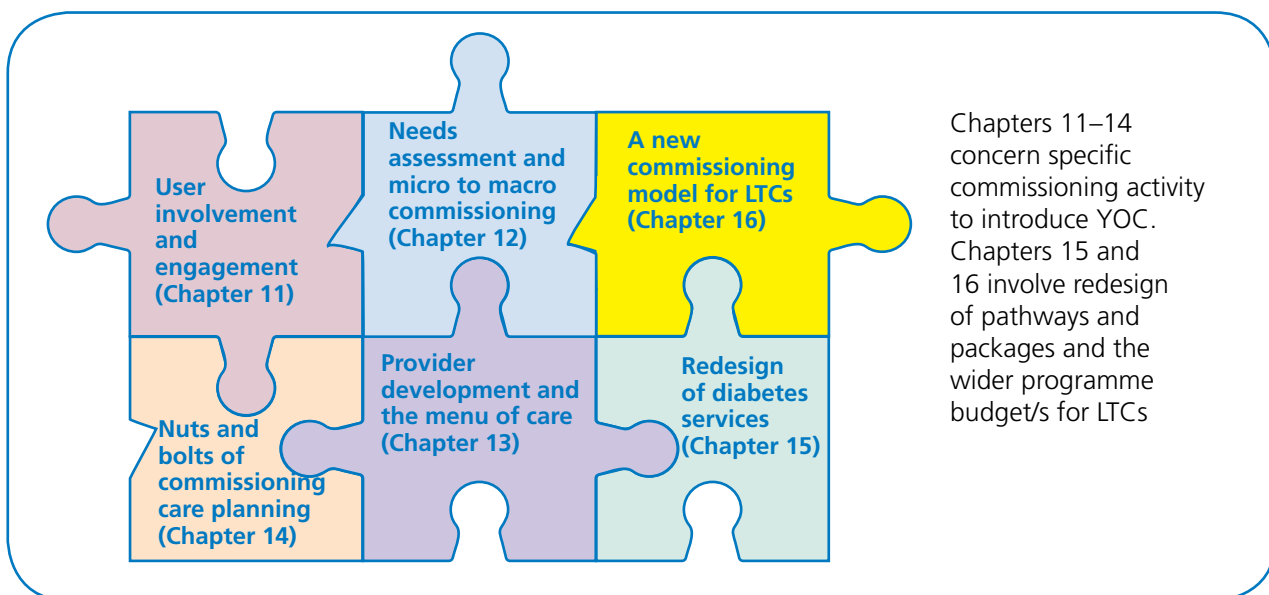
Figure 29: The initial model used by pilots to help identify the YOC commissioning tasks and the links with the wider local commissioning agenda



The Windmill, whilst helpful at an early stage, was found to be less relevant as the detail around YOC commissioning developed. It was however, a key piece of thinking in the development of YOC and showed that establishing YOC within a wider strategic commissioning strategy would be helpful for those embarking on this journey.

Subsequently the commissioning components coalesced into six main areas of interlinked development work as shown in Figure 30. The detail of each can be found in the chapter indicated.

Figure 30: Commissioning components areas of development work



Chapter 11: User engagement in commissioning and service design

This chapter considers the issues of wider user engagement across communities to inform the design, delivery and commissioning of local diabetes services.

Key points

- One size does not fit all – a variety of engagement methods needs to be used.
- Both the engagement of individuals in care planning (Chapter 6) and the wider involvement needs itself to be resourced and commissioned.
- Detailed examples of effective local solutions are provided in the case summaries.
- This experience should be of interest to developing health and well being boards.

Chapters 6 and 9 summarised the successful engagement of people from diverse communities across Tower Hamlets throughout the Project, and the increasing activity in Kirklees. This was achieved by coordinating the work to make it easier for individuals themselves to take part in care planning, with wider engagement across the entire community.

The Year of Care (YOC) Board and all pilot sites committed to involving people with diabetes as part of the national and local steering groups respectively. They participated in the learning sets contributing to the design and development of all elements of the programme, made presentations and spoke on behalf of the Project, playing a critical role in interviewing, recruiting to and evaluating the learning from, the project as a whole.

In Tower Hamlets, user engagement was particularly strong and included a range of activities. They built on existing relationships to work on health issues with community and faith groups and ran large engagement events around diabetes and smaller focus groups, identifying problems in the current way services were delivered and providing solutions to address them. Information was also tailored for individuals in accessible formats. Links were assisted by including the well-networked Patient and Public Involvement lead (Assistant Director level) on the YOC Steering Group as a whole. This interlinked with other work streams pertaining to patient education and supporting self management through the Expert Patient Programme. Their learning showed that it is essential for a variety of different stakeholder engagement approaches to be in place for maximum effect.

Supporting patient engagement in service design

Patient engagement to inform service design and commissioning is not without cost. It might be envisioned that some activities will only be needed once or less frequently, depending on the stability of the population and the levels of satisfaction with improvements; the routine resources (eg information sheets/ folders for results) are an ongoing expense (not restricted to care planning). Nevertheless, involvement of the local

population in regular and ongoing service review and improvement is a key component of all high quality commissioning and relevant resource needs to be identified for this.

The infrastructure to support user engagement in self management activities needing to be commissioned is described throughout this report and the case studies. This includes:

- non-clinical staff training and development
- training advocates and reception staff from local communities, health trainers
- IT
- materials for people with diabetes – both written and in mixed media
- better mechanisms for routinely collecting patient feedback
- electronic and paper resources to link with the menu of care to inform people with diabetes
- commissioning of non-traditional services providing non-clinical services to support wider therapeutic as well local cultural requirements and social needs
- engagement meetings at practice and community level (eg timing to avoid prayers and mealtimes)
- ideas stores and libraries
- use of relevant media, eg local papers and community radio stations to support delivery of health messages
- pre care planning group activities to explain test results and improve health literacy (three out of eight Tower Hamlets practices)
- structured education and courses (Tower Hamlets and Kirklees).

Future issues

Many people with diabetes mentioned the potential for online platforms and electronic access to their own health records to support self management, engagement and feedback. This supports the wider call for patients to have greater access to their own records¹⁰⁶. Others mentioned the development of phone applications (apps) which could help people with lifestyle changes or with service feedback.

As yet, no robust technology platforms have been identified that are fully able to support the YOC vision. However, we should certainly ‘watch this space’ as web-based tools emerge to support understanding and engagement. For example the Young Foundation’s ‘Maslaha’ an award-winning website aimed at connecting “technology with the community to create incentive and effective resources to tackle issues around health and education” (www.maslaha.org).

These experiences should highlight issues for communities where the disadvantaged are either less visible, make up a smaller proportion of the population or exist in pockets of deprivation within advantaged communities because of poor literacy or poverty. Health equity assessments need to address whether there are pockets of particular need which may need more innovative responses.

Nationally, developing a robust structure to enable sharing of lessons, resources and materials developed, eg DVDs would be of great value. This whole area is likely to be of key interest for the emerging health and wellbeing boards, which are likely to enable more effective triangulation of patient engagement and feedback from within the health sector, with intelligence and understanding from borough and local government perspectives.

Chapter 12: Needs assessment – self management

This chapter examines micro and macro commissioning and the use of social marketing and ‘packages of care’ to meet the needs of local diabetes communities.

Key points

- Effective micro to macro commissioning will depend on availability of IT systems for care planning intimately embedded in the Electronic Health record (EHR)
- These systems became available for use as the Year of Care (YOC) Project phase came to an end.
- They will be implemented first in Kirklees as part of the Local Improvement Scheme (LIS) agreement with practices over the next year.
- Social marketing was useful to identify the range and volume of services needed, but group classification must not artificially constrain choice for individuals.
- Stratifying the population along biomedical lines provided the basis for packages of care in Tower Hamlets.

The second component of the YOC programme was to use care planning as a means of identifying the services people would value to assist them to achieve their goals and carry out their action plans over the year following the care planning consultation itself. The potential was both to provide a far more tailored set of therapeutic and support services, and also more choice, that could dovetail with more clinical routine review appointments. This could involve a much wider array of third sector and independent providers of supported self management (SSM).

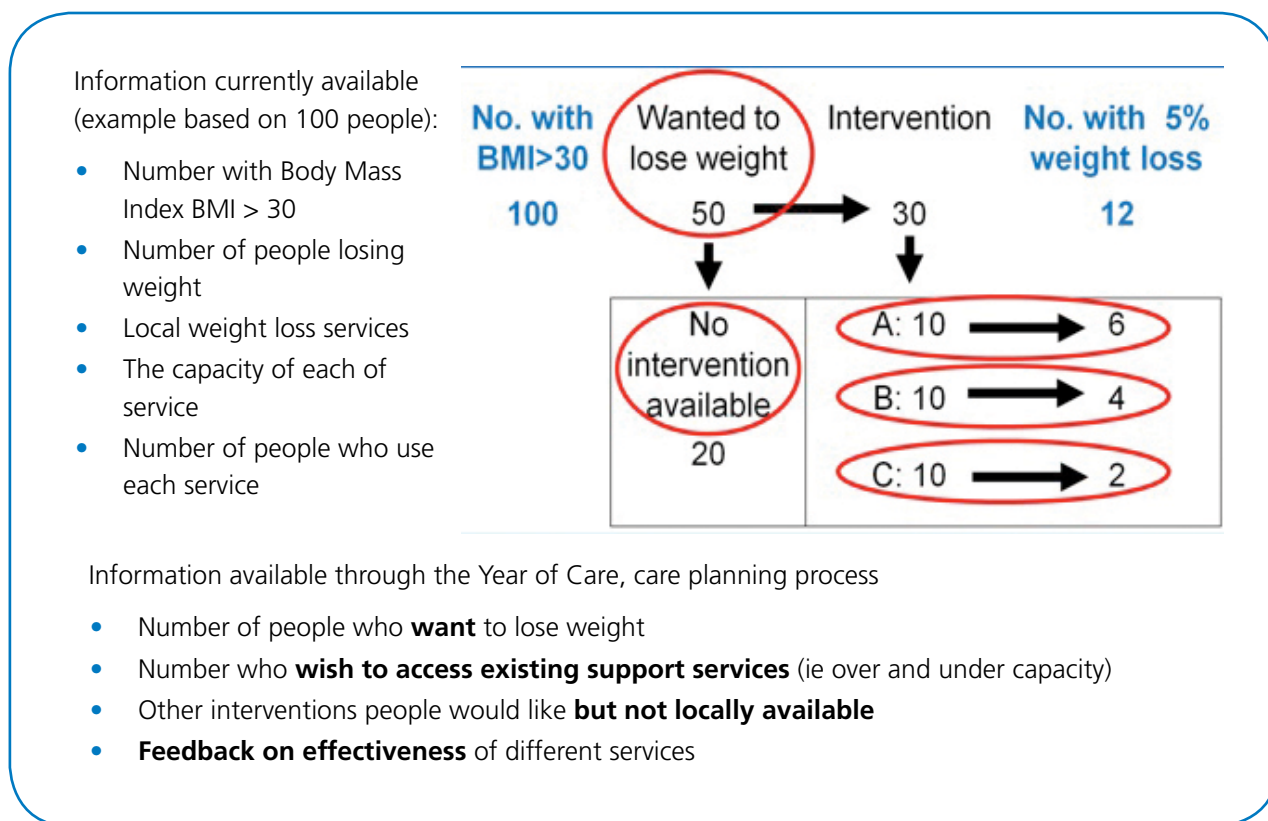
The broader perspective of ensuring access to a wider range of socially and community based services outside of the clinical setting, but linked to it, is fundamental to the YOC concept of commissioning support for self management, and led to three of the six ‘project questions’ of the YOC programme namely:

- how to systematically link individual choices and actual service use (micro commissioning) into population level commissioning (macro commissioning)
- how to identify sections of the local population by potential needs for services to support self management
- how to develop new and existing providers to support self management.

How to 'capture' individual needs identified during care planning (micro commissioning) for use in macro commissioning

Commissioning services that people want and use is not only important for people with diabetes, but important for the local health economy, ensuring that scarce resources are spent effectively and wisely. Currently, commissioners do not have all the information they need. This is illustrated in Figure 31.

Figure 31: What do Commissioners want to know to help more people achieve significant weight loss (5% body weight)?



Obtaining this information is dependent on reliable IT systems which enable clinicians to record unmet need at the time of the consultation and record outcomes either at the review appointment or directly from the service provider. The difficulties encountered with developing an appropriate IT system during the duration of the Programme are outlined in Chapter 6.

Fields to enable recording of unmet need are now integral parts of the YOC IT specification and components of the modules under development by the major system suppliers see Figure 32. This aspect is just starting to be tested in Kirklees and will be used by some of the new sites coming on stream in the near future:

“Kirklees practices are just getting their heads around the first year of care planning itself – and it will take longer to link it all together in a more cohesive way.”

Figure 32: Example from a care planning Ve Form (Vision) designed to the YOC specification showing a goal, action plan and facility for recording unmet need

The screenshot displays a form titled "No. 1 Goal & Action Plan". It is divided into two main sections: "Goal" and "Action Plan".

Goal Section:

- What do you want to work on?** weight loss
- What do you want to achieve?** patient would like to lose about a stone over the nex
- How important is it to you?** 10
- Category** Prevention/ Management of complications
- Type of Goal** Improve (selected), Maintain

Action Plan Section:

- What exactly are you going to do?** join Weight Watchers
- What might stop you, and what can you do about it?** I might be tempted to have chips on Friday night.
- Category** Self-Care Approach
- How confident do you feel?** 10
- Method cannot be met (e.g. the service is unavailable locally)** []

How to identify sections of the local population by potential need for services

There were two reasons why it was important to identify different sections of the population by their need for services. The first, specific to the YOC approach, was to ensure that a menu of options existed to enable people to choose the most appropriate service to support them in self management. The second, a wider agenda in health policy, was to ensure that resources were appropriately targeted to those with greatest need.

Various different approaches were identified as potential ways of linking non-traditional service providers to achieving these ends and some were used by pilot sites:

- Moments in care: these form the basis of many traditional guidelines and pathways, eg at diagnosis, first complication, need for additional social support, etc.
- Stratifying the population of people with diabetes into groups using biomedical indicators and measures and then specifying the service input, and payment structure, required for each. This approach was used to inform the development of care packages in Tower Hamlets (Chapter 14 and Appendix 5).
- Needs identified by resource use: patterns of emergency admissions, non-scheduled appointment etc.
- Social marketing segmentation: identification of characteristics to match against population subgroups which might indicate the need for a specific form of intervention, focussing on those who need things most.

Many of these were described in *Getting to Grips*¹⁰⁷ and included focus groups to inform the development of an organic approach to identifying the clinical, educational and social support needs of subgroups of the diabetes community at all sites, using a variety of social marketing techniques as described below.

107 Year of Care. (2008). *Getting to Grips with Year of Care: A Practical Guide*

Applying social marketing techniques to segment population groups

During Year 1, Calderdale and Kirklees conducted some in-depth focus groups with clinicians and people with diabetes, identifying important issues and differences about how people with diabetes manage their condition, explored from different perspectives. People were segmented as 'managers' and 'strugglers'. In the focus groups, this provided an insight into how it might feel to have diabetes. For clinicians, it raised the issue sometimes for the first time. It was clear that people with diabetes had differing approaches to living with diabetes, and defining these approaches and gearing the service response to them might prove beneficial for all.

In Tower Hamlets, a wider but similar classification was achieved in the context of how best to target educational services. This led to a greater understanding of the range of different approaches to self management and the confirmation that one size does not fit all. This led to the range of educational opportunities being developed.

The Programme Board and central team noticed that language used in these gatherings was often disparaging, and many of the teams felt uncomfortable about this. The initial segmentation approach used locally, was useful for categorising the needs of a subgroup of the population to inform commissioning and public health campaigns, however there was concern that the 'classifications' should not transfer to the individual clinical encounter (ie '*you are a struggler!*'). To avoid this dilemma, more sensitive classifications (eg 'needing support') can be applied to ensure consistency with YOC philosophy and to be more constructive to prevent the use of judgemental and paternalistic language when discussing directly with people with diabetes during care planning consultations. There is also a separate danger that this information is used in the clinical encounter at all. The care planning approach is about supporting individual to identify, clarify and articulate their own needs.

'Packages of care'

The second approach was identifying groups of people by a 'package' of issues around which to develop payment structure and tariffs. This became the basis of the Tower Hamlets 'packages of care'.

Initially, these have been determined entirely by biomedical issues of control and services required, rather than any of those related to measured capacity to self manage. As such packages of care bed down, it is recognised that more flexible and individually tailored approaches need to be developed, and that it is inappropriate to 'straight-jacket' people into unnecessarily rigid structures of care.

Chapter 13: Provider development and the 'menu of care'

This chapter discusses how to develop the 'menu of care' and provides a guide on how to develop and commission non-traditional services (such as voluntary organisations, community groups and social enterprises) to support self management for people with long term conditions (LTCs).

Key points

- Assessing the availability of different support services for people with diabetes, many outside the traditional healthcare setting, is a prerequisite for developing a local menu.
- Problems were identified with identifying services and commissioning new ones
- A range of solutions is described.
- Non-traditional providers such as voluntary organisations, community groups and social enterprises can provide tailor made solutions to support people with lifestyle choices, peer support and social contact to reduce isolation, and increase knowledge and confidence leading to better health outcomes.
- YOC has produced a guide *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Providers*⁹⁶ to support more effective commissioning of community based services to meet the wider social self-management support needs of people with long term conditions.

Identifying the menu of support services for people with diabetes

While pilot sites were identifying need from a variety of angles they also set about reviewing current service provision. They identified services to support lifestyle change from a wide range of providers, outside of the traditional NHS settings. Some were not known to the PCT or local practices. Some were based in the local authority, public health or community sectors. Some were very local, and there was not always a direct link with the needs of the surrounding population. Each site began to pull these together into a 'directory of services'. All were paper-based. These were made available to practices and the local population through libraries and high street shops.

Problems identified:

- information is rapidly out of date, with no job role designated to update it
- directories sit easier on the shelf than in the forefront of a clinician's mind
- only some services were delivered via referral, often the individual must make contact themselves
- the non-traditional services were patchy, arising from short-lived funding
- the availability of non-traditional services were not necessarily linked to the needs of local individuals
- few had direct links with primary care.

108 Year of Care.(2011). *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self Management of People with Long Term Conditions*. (Online) Available from www.diabetes.nhs.uk/year_of_care/commissioning/thanks_for_the_petunias_a_guide_to_developing_and_commissioning_nontraditional_providers

Finding solutions

Individual signposting

- Tower Hamlets commissioned Social Action for Health, a local third sector provider, to provide a range of in-house and outreach services for the South Asian community, supporting people identified in practice and providing specialist resources (eg cooking classes for South Asian Men).
- Health trainers in Kirklees provide a referral service of tailored support to help people work on their goals and action plans.

Directory development

- Tower Hamlets commissioned an online directory – this was designed, and will be managed by, the Healthy Lifestyles team from within the Public Health Directorate who will update it regularly. When the EMIS Web IT facility is rolled out, it will be possible to link website addresses into data entry templates to enable clinicians to access information about services more easily during the consultation.

Public health initiatives

- A programme of community initiatives developed by public health was expanded under the YOC stimulus in Kirklees. This included Expert Patient Programmes for South Asian Women.

Developing new providers

- Following their comprehensive needs analysis, Kirklees held two workshops for interested local providers to stimulate interest in developing new services. The PCT was able to commission changes to the traditional diabetes services in both the acute trust and community unit, as well as a major information resource for people with LTCs via the local authority. However no new third sector or independent providers emerged.

Tackling the problem

Recognising that non-traditional providers (such as voluntary organisations, community groups and social enterprises) are often deeply embedded in the communities they serve and can provide tailor-made solutions for the needs of people with LTCs, the YOC Programme began a new piece of work to see how this might be delivered.

During 2009, the YOC Programme Manager surveyed those PCTs with high overall scores for World Class Commissioning (WCC), or who were known to be interested in this area. The 19 detailed replies generated the following findings. There were:

- no Provider Development Managers in PCTs
- no incentives for providers to enter the market
- no change management support
- few non-NHS services
- no work activities to develop community providers
- strong views emerging were that *'public health does that'* and *'I'm not sure PCTs know what to do'*. The World Class Commissioning competency scores for that year also revealed that provider development of any sort scored the weakest of all the competencies.

The North of Tyne YOC pilot successfully secured NHS Northeast Innovation Funds to identify the challenges and barriers to provider development and produced guidance and suggestions for how to overcome them. They drew together the experience from the pilots, sought examples from elsewhere and built on the experience of a local third sector organisation (HealthWORKS Newcastle), which was already linked with local primary care teams via health trainers.

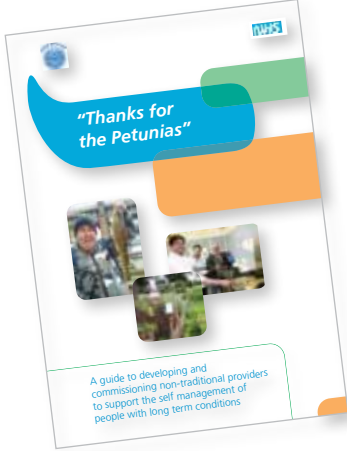
The outcome of this work is a new model of provision described in the YOC publication *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Providers to Support Self Management of People with Long Term Conditions*.¹⁰⁹

109 Year of Care. (2011). *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self Management of People with Long Term Conditions*. (Online) Available from www.diabetes.nhs.uk/year_of_care/commissioning/thanks_for_the_petunias_a_guide_to_developing_and_commissioning_nontraditional_providers

Figure 33: Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Providers to Support Self Management of People with Long Term Conditions

This guide helps to address:

- Self management of LTCs
- Health inequalities
- Personalisation
- Sustainable commissioning



It contains:

- Top tips
- Practical examples
- 'How to do it' suggestions

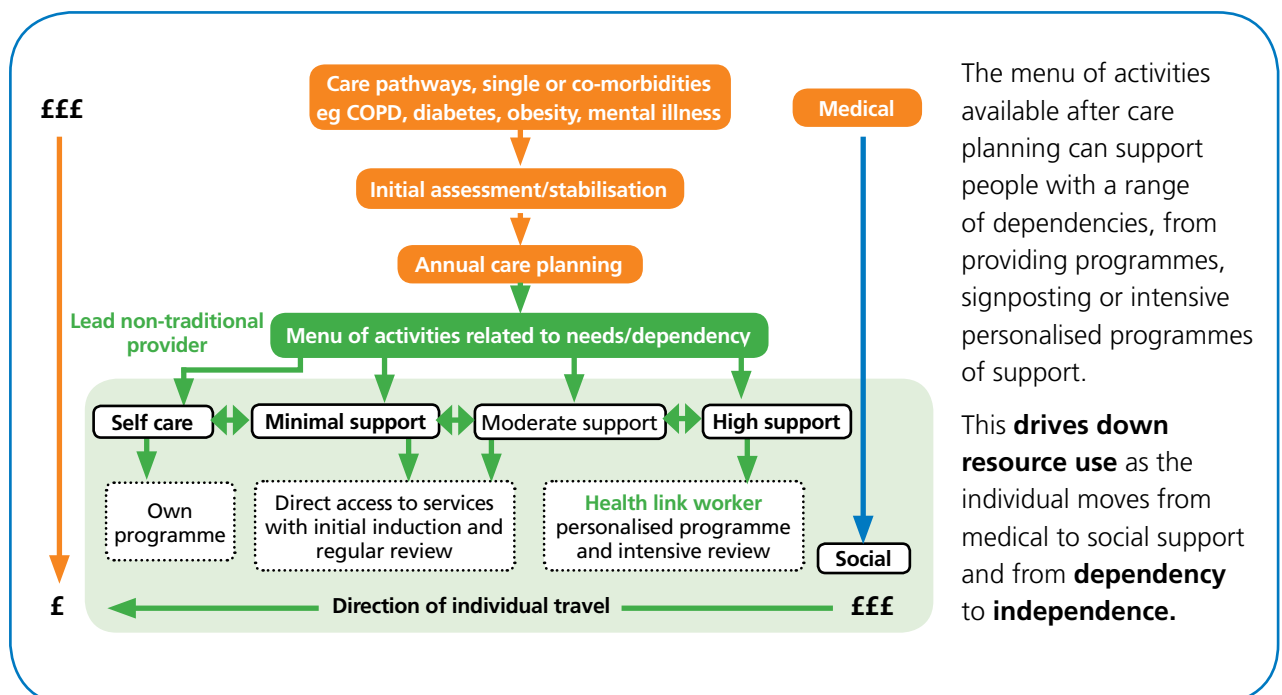
Issues addressed in the report include:

- non-traditional services (including 'lifestyle support') are often not seen as 'therapeutic' by clinicians
- clinicians lack knowledge about and confidence in local services
- mechanisms are not flexible enough to support multiple small providers and commissioners are inexperienced in this area
- how to identify, measure and feed back quality outcomes to referring teams and commissioners.

The guide provides:

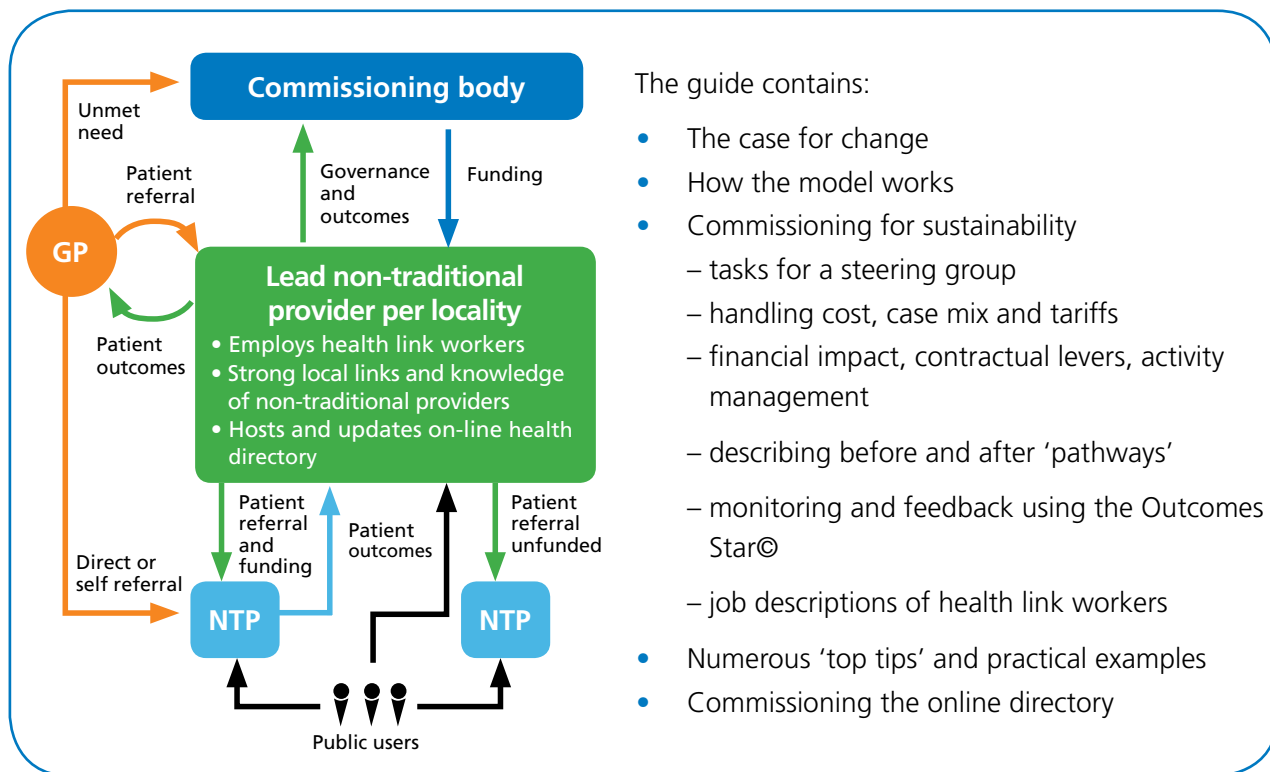
- 1: A framework to demonstrate the improved outcomes and cost benefits of linking care planning to community SSM (Figure 34).

Figure 34: How to systematically link care planning and community SSM



2: A suggested commissioning model based on a lead non-traditional provider, which overcomes a majority of the barriers and issues identified above (Figure 35).

Figure 35: Framework for engaging non-traditional providers in the commissioning of healthcare services



The future

This work was completed after the end of the YOC pilot phase, and its use in practice will be tested in the next phase of the YOC programme (Chapter 18). Opportunities exist to look innovatively at supporting people with LTCs to review goals and action plans in the context of their clinical, emotional and social needs as part of pathways and packages of care drawing on the wider social model of health.

“The staff are very respectful to individual needs and make everyone feel special. They empowered me to make choices about my lifestyle and did not judge when things may go wrong.”

A person with multiple LTCs talking about health link workers from a local non-traditional provider¹¹⁰

110 Year of Care.(2011). *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self Management of People with Long Term Conditions*. (Online) Available from www.diabetes.nhs.uk/year_of_care/commissioning/thanks_for_the_petunias_a_guide_to_developing_and_commissioning_nontraditional_providers

Chapter 14: Commissioning care planning – the nuts and bolts and currencies

This chapter discusses the nuts and bolts of commissioning care planning in each pilot site and how this was developed over the project. The issues of currencies and tariffs for Year of Care (YOC) is discussed.

Key points

- Care planning will not take place unless it is commissioned.
- Commissioning must include the care planning process itself, and the support for infrastructure beyond the practice including training, facilitation and user engagement.
- The potential of developing packages of care, tailored quality incentives and performance monitoring to facilitate more effective commissioning of personalised care is only just beginning to be explored.
- Currencies for long term conditions (LTCs) need to be local rather than national because of the complexity of service provision and the different strategic objectives which commissioners will wish to incentivise. They may include elements reflecting the complexity of care, quality makers as well as period of time.
- Currencies of non-traditional providers are more complex and would benefit from having components for quality, incentivising good practice including sustaining behaviour change.

Care planning, as described in this document, requires clinical teams to develop new skills and use resources in new ways. It therefore impacts directly on commissioning, indeed commissioning is the foundation of the House model.

It is possible for a single practice, or a clinical team that controls its own budget and buildings (possibly within a diabetes centre) to make many of the changes that are involved, and may even save money if they can use staff differently and more efficiently. However, commissioning a group of teams or practices has many advantages. It helps mitigate against double running costs where a practice may have to incur the costs of the old system running in parallel with the new system before staff roles can be changed during set up, and spreads the costs of IT support and training. Economies of scale mean that training is best delivered to a group of around 10 practices. Working in groups and with the relevant specialist teams enables new staff to be trained as they are appointed and high quality materials for people with diabetes to be produced in bulk.

The pilot sites all used commissioning to resource and incentivise their pilot practices. Then having learnt about what works and made care planning successful, each developed new structured arrangements to spread this across a majority of practices in their localities.

The key features they needed to consider were:

Agreements with the provider practices

- Ensuring complete registers of all people with diabetes and a clear understanding of where the annual care planning or surveillance review will take place.
- Actions to be taken by the practices to implement care planning (may include quality and frequency).
- Actions to be taken by the practice to monitor care planning.
- A developmental approach to include increasing participation, involvement in training and mentoring, multi-disciplinary meetings (MDT) meetings, audit.
- Reporting and monitoring structures.
- Payment structures.

Provision of support to provider practices

- Training.
- IT/resources including those for patient engagement.
- Ongoing facilitation.

Agreements with provider practices (LES and LIS arrangements)

Each site chose to deliver these functions in different ways, based on historical arrangements or their wider local commissioning strategy. In each case, care planning became part of a wider Local Enhanced Service (LES) or Local Improvement Scheme (LIS) in Kirklees, which included primary care provision of a range of diabetes services over and above the GMS /PMS requirements. In each case, the mechanism used was also part of a wider strategy to reshape the provision of diabetes care across the whole community. (This aspect is considered in the next section).

Brief outlines of the arrangements at the pilot sites are given in Appendix 5.

Commissioning care planning: general features

As YOC involvement spread to non-pilot health communities via training, differing arrangements for incentivising care planning emerged, based on local circumstances.

Tables 10 and 11 outline some of the elements which were included. They all acknowledge that since care planning is relatively new, agreements need to include a variety of core and developmental components. These commissioners all made separate provision for support activities (quality-assured training, educational activities, IT support, and user engagement).

Table 10: Features in all LES agreements

- A lead individual within the practice
- A statement of the local model of care for diabetes ie where each person with diabetes should have care planning (the denominator for monitoring)
- A requirement to keep a register
- A requirement to assess staff competencies (against a recommended list which usually maps to national competency frameworks but may include others) and to ensure they are up to date and include new staff
- A requirement for test results to be made available to the individual in an understandable format one to two weeks before the consultation
- A requirement for staff to have received quality assured care planning training
- A requirement for information about the care planning process to be provided in an appropriate format for the individual
- A requirement for individuals to receive a summary care plan in accessible format after the consultation and for it to be recorded systematically on the electric health record (EHR) so it can be accessed as part of their ongoing diabetes care
- A requirement for arrangements to be made for those with health literacy or language issues
- A requirement for appropriate arrangements for vulnerable or disadvantaged groups relevant to the practice (BME, disability, housebound, travellers, residential homes)
- A requirement to make anonymised data available to Commissioners

Table 11: Features in some LES agreements

- Production of a structured annual report
- An outline of the expected care planning 'pathway' (may include contact time, staff grades frequency of activities, etc (see Figure 26 and Appendix 5)
- Codes to be used
- Taking part in ongoing educational activities, eg sharing of data and peer review of care planning
- Monitoring the 'quality' of care plans
- Providing examples of outputs of care planning (goals and their achievement over a six month period) for the purpose of monitoring quality and tailoring further education
- Reporting of unmet need for services to support self management in the community in anonymised form (IT dependent)
- Reporting the use and usefulness of community services to support self management in anonymised form (IT dependent)

Monitoring arrangements

The delay in developing national templates and codes for care planning (see Chapter 6) contributed to a lack of a consistent approach, though an Outcomes Framework (see Chapter 6) is now available. That said, each commissioner will want to measure those aspects they wish to incentivise locally, so complete consistency is not necessarily desirable.

Some Commissioners choose to monitor the output of care planning (ie number of care plans) and take the risk of encouraging a ‘tick box’ activity. Others aim to incentivise the new approach and the process of care planning. They opt for proxy measures, such as recording whether test results have been sent out and attendance at educational activities (Table 12). Some, including pilot sites, are allowing self-reporting that care planning has taken place. Most are highlighting their intention to include exit questions or questionnaires, ‘mystery shoppers’ or other means to assess this more formally in the future.

Table 12: Examples used for monitoring performance in LES agreements

Numerical indicators sometimes use standard and stretch levels (with linked payments)
The production of a structured annual report includes:
% of registered patients who have undertaken care planning (increasing year on year)
% of individuals who had test results sent out prior to the care planning appointment
% of individuals who have received test results prior to the care planning appointment
% of individuals who have received a summary care plan in accessible form
% of review or educational meetings attended
Objective completion of the care planning template provided to the system
Developmental
Practices that have completed self reflection tools and/or personal development plans for a specified number of patients
Increasingly positive scores for an exit question or questionnaire

Table 13: Financial arrangements

A variety of payment methods are in use:
Some make a distinction between payment for involvement in the process, and payment for activity.
Some pay for a percentage of the registered population or for the numbers of individuals to have been involved in care planning.
Most include other elements of diabetes care over and above care planning.
One LES included the requirement for ‘open book’ arrangements during the first year to enable better assessments of costs of care planning to be made.

Commissioning care planning in the future

All the sites that have been part of the YOC Programme or received the National Care Planning Training Programme are moving towards making care planning routine for people with diabetes, and either extending it to other LTCs or considering doing so. The RCGP has recommended that care planning should be introduced as a professional standard for GPs supporting people with LTCs, and NICE has identified care planning as one of 13 Quality Standards for diabetes. In light of this, it is important to consider how both care planning itself and the services to support it might be commissioned in the future.

Currently it is unclear what guidance the National Commissioning Board will provide about payment for activities by GP providers where part might be included in basic (‘new GMS’) care and part locally commissioned. Local commissioners will have to be guided, or decide, whether they continue with ‘LES-like’ mechanisms for all or part of such a process. Long term, care planning might be considered part of routine care, with consortia commissioning for the additional resources required at start up, for very disadvantaged

populations and for ongoing training and coordination. It would seem advantageous for the Commissioning Board to encourage such local flexibility. This is an area that would benefit from testing by Pathway Consortia, supported by the Royal College of General Practitioners (RCGP) care planning and commissioning initiatives.¹¹¹

Currencies and tariffs – the issues

The phrase 'year of care' was first used by Prof Pieter Degeling to describe an approach to developing a currency for people with LTCs who were using secondary care services¹¹². Their legitimate need for repeated contact or admission for the same condition or conditions led him to suggest a tariff for care provided over a period of time rather than for each episode.

The YOC Programme was seen as an opportunity to investigate this idea in practice.

Diabetes affects almost every organ of the body, and during their lifetime an individual may receive care from every part of the NHS / social care. The relevance of this experience for other LTCs is indicated in the workforce matrix (Chapters 5 and 8). The YOC Project focussed on the routine care of people with diabetes (Chapter 15). For the majority of people with Type 2 diabetes this takes place in primary care and the majority of people with Type 1 diabetes in specialist settings.

A majority of effort during the YOC project was devoted to working out the details of service provision at a particular site of care (predominantly primary care) rather than the details of referral between organisations. However the importance of developing currencies and tariffs for LTCs and for use in the 'community' was recognised by the project from its outset.

Problems related to the current tariff structure were recognised by the pilots as they tried to redesign services and specific examples of the approaches in use or developed are summarised here. A number of these have been mapped onto the YOC commissioning model for LTCs (Chapter 16). As care planning beds down into routine practice, and especially as it is linked to ongoing care provided in non-traditional community settings (Chapter 13), greater experimentation with new local currencies and tariffs will become possible. The examples below show that such currencies need to be local rather than national because of the complexity of service provision and the different strategic objectives which commissioners will wish to incentivise.

Purchasing specialist care

The currencies for inpatient care were not a focus of the project. However, all pilots were frustrated by the perverse incentives under the current Payment By Results system which encourage acute trusts to maximise income from outpatient specialist care, rather than looking at other payment mechanisms to enable delivery of specialist care within the community to support self care. Tower Hamlets found there were no incentives to redesign consultant job plans to incentivise new ways of working, including either direct or indirect support for primary care, or work with multidisciplinary teams. They argued that sessions in the job plan designed to support patient activity (SPAs) should be used for these activities in LTCs. At least one of the local consultants was paid in this way to attend the Multidisciplinary Diabetes Team (MDT) meetings which were an integral part of the new diabetes packages of care.

Innovative approaches based on much greater integration of primary and specialist services that negotiated mutual cost reduction for the acute trust and commissioner, and /or included a CQUIN like payment (www.institute.nhs.uk/world_class_commissioning/pct_portal/cquin.html) for specialist providers based on LTC outcomes across the whole local population would be desirable.

Purchasing traditional community care

Many of the functions needed to support a high quality care planning process in primary care, are linked to components traditionally provided by community services (Chapter 15) such as nutrition, podiatry, psychology, retinal screening and some elements of specialist nursing. Traditionally these are paid for by a variety of

111 <http://commissioning.rcgp.org.uk>

112 Degeling, P. www.researchoption.co.uk/YOC_docs/pres6.pdf

mechanisms which are not transparent, or are parts of block contracts held with community provider units for a wide range of service. Tower Hamlets were able to devise a system of local tariffs for these services in parallel with the work on packages of care, although this was not strictly part of the YOC project.

Purchasing basic/routine care from primary care

The majority of contacts with people with diabetes and other LTCs happen in primary care. Primary care is already remunerated through GMS and QOF payments for case finding, and certain process and intermediate outcomes. For diabetes, and increasingly other conditions such as hypertension, asthma and coronary heart disease, contacts take place within a structure of care, usually, but not always, in protected time. This was the main focus for YOC which recommended that structured care planning (even if not in designated 'clinics') should become the norm for the majority of people with LTCs.

All pilot sites paid for this additional element via some 'time related' currency – ie annual payment for specific activities for identified individuals, in the form of enhanced service contracts. Tower Hamlets moved on to develop 'packages of care' specifically arranged around care planning, and complexity of need of each individual, thus including a level of 'complexity' as well as 'time' in the currency. These packages accrued different levels of payments (tariffs), which were aggregated by the networks either to pay individual practitioners or to purchase additional support services at network level from the other parts of the service.

National Guidance on these multiple payment methods from the new Commissioning Board would be welcome. As care planning becomes routine it seems foolish to pay for it separately, and incorporating care planning into new GMS arrangements for everyone with LTCs would make sense. Local additional payments could be used for set up, providing data for monitoring and improvement, stratification by complexity and risk, and for those needing extra input. Local commissioners would also purchase the support services, training and wider user engagement often at network or 'federation' level.

Purchasing services to support self management from non-traditional community providers

The challenges of purchasing services from the third sector and smaller non-traditional community providers were one reason why provision was both fragmented and inadequate. The issues involved and suggested solutions are discussed in the YOC document *Thanks for the Petunias – A Guide to Delivering and Commissioning Non-Traditional Providers to Support Self Management of People with Long Term Conditions*.¹¹³ This includes a greater understanding of the role of grants and tariffs, and the issues of funding from the perspective of the provider (Appendix 8 of that document). There is a particular need to incentivise providers to help individuals sustain healthy behaviours. Providers currently benefit when people fail and have to be repeatedly referred. The document makes suggestions about how this might be addressed. As care planning becomes the norm, and is linked with community providers through the overarching YOC model the potential to purchase 'years of care' from these providers will become a reality.

113 Year of Care.(2011). *Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self Management of People with Long Term Conditions*. (Online) Available from www.diabetes.nhs.uk/year_of_care/commissioning/thanks_for_the_petunias_a_guide_to_developing_and_commissioning_nontraditional_providers

Chapter 15: Care planning and diabetes service redesign

This chapter describes where care planning fits within local diabetes services as part of the local healthcare system, how it supports delivery of the NICE diabetes in adults quality standard¹¹⁴ and the consequent issues for service redesign.

Key points

- Care planning is a key component of routine services for everyone with Type 1 or Type 2 diabetes.
- It needs to be introduced as part of a service model which integrates all aspects of diabetes care 'Diabetes Without Walls'.¹¹⁵
- Nine of the 13 statements contained within the NICE national Quality Standard¹⁰² relate to routine diabetes care and can best be delivered by a service designed around structured education and care planning.

Chapter 9 described the redesign of pathways within practice teams to support care planning. This chapter describes the wider changes in diabetes services which became necessary. The essential components of a quality diabetes service that people with diabetes should expect were outlined in the National Service Framework in 2001¹¹⁶ and have recently been summarised in 13 National Quality Standard statements recommended by NICE for use by the developing NHS Commissioning Board. Care planning is a key component of both these documents. The expectation is that collaborative care planning will deliver a more personalised and engaged approach to support self management, than the traditional annual surveillance reviews currently delivered in diabetes care and thus be recognised as a routine part of care for everyone with diabetes.

114 National Institute for Health and Clinical Excellence (NICE). (2011). *Diabetes in Adults Quality Standard*. (Online) Available from www.nice.org.uk/guidance/qualitystandards/diabetesinadults/diabetesinadultsqualitystandard.jsp

115 NHS Diabetes. (2009). *Commissioning Diabetes Without Walls*

116 Department of Health. (2001). *National Service Framework for Diabetes: Standards*

Figure 36: The components of diabetes service (NSF 2003)

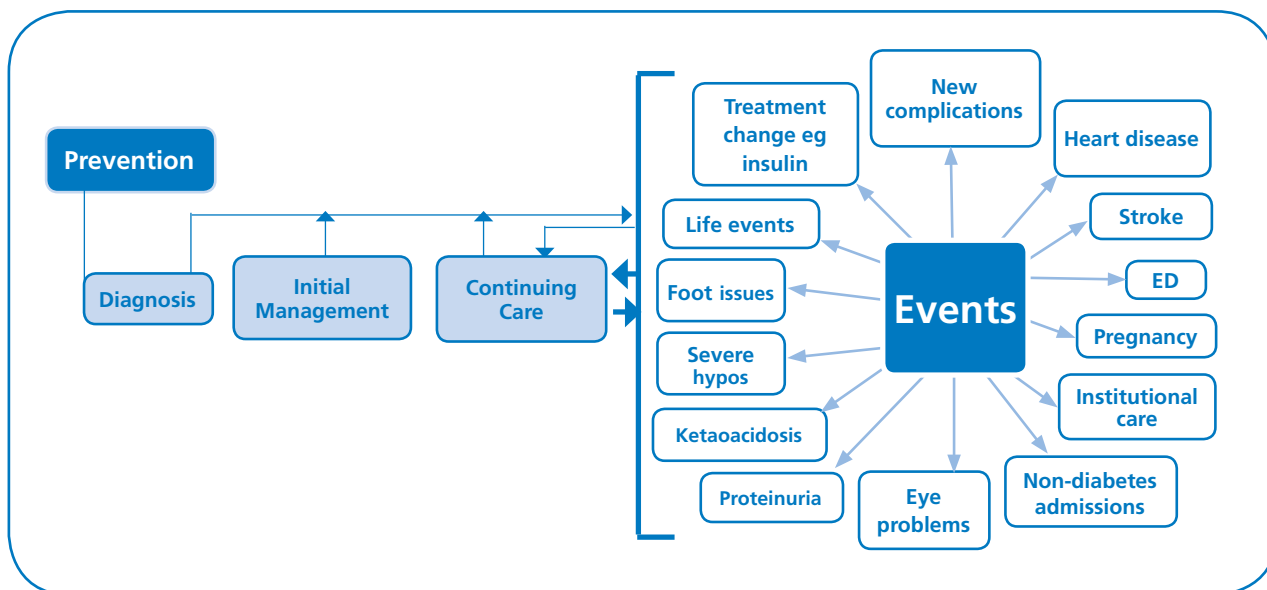
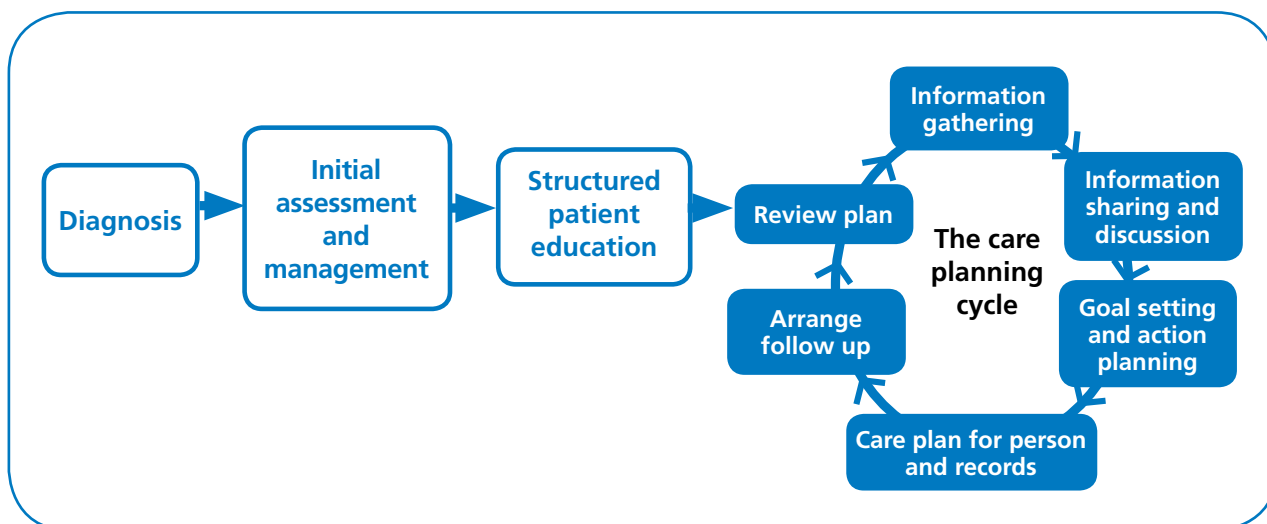


Figure 36 maps the typical interventions people with diabetes will need access to within their clinical care pathway through a lifetime of living with diabetes taken from the NSF¹¹⁷. Care planning sits within the continuing care component of the tail of this ‘tadpole’ diagram. Expanding this demonstrates where the core components of care fit together (Figure 37).

Figure 37: Components of routine care for everyone with diabetes



The pilot sites found that as they redesigned primary care to deliver this process for a majority of people with Type 2 (and some people with Type 1) diabetes this had knock on effects for the specialist service. Rather than be involved predominately via referral, or intermittent training, a great deal of specialist input was needed to support delivery of the key care components above, including care planning, or to coordinate with the outputs. One example is the new Multidisciplinary Diabetes Team (MDT) meeting commissioned by Tower Hamlets as part of the new diabetes packages of care (Chapter 14). This is a practical manifestation of the principles of modern diabetes care, as outlined in *Commissioning Diabetes Without Walls*¹¹⁸, to deliver integrated diabetes

117 Department of Health. (2003). *National Service Framework for Diabetes: Delivery Strategy*

118 NHS Diabetes. (2009). *Commissioning Diabetes Without Walls*

care with primary and specialist functions, (and now to include non-traditional providers), working together to provide the expert input needed by people with diabetes without the automatic need for individual referral. This provides continuity of care and a seamless experience for the person with diabetes but also assumes an important role for coordination, which must be recognised and commissioned for.

For local diabetes services considering introducing the Year of Care (YOC) principles, Figure 38 provides a checklist of what needs to be in place to make this happen:

Figure 38: Checklist – designing a diabetes service to support and develop high quality routine care for everyone

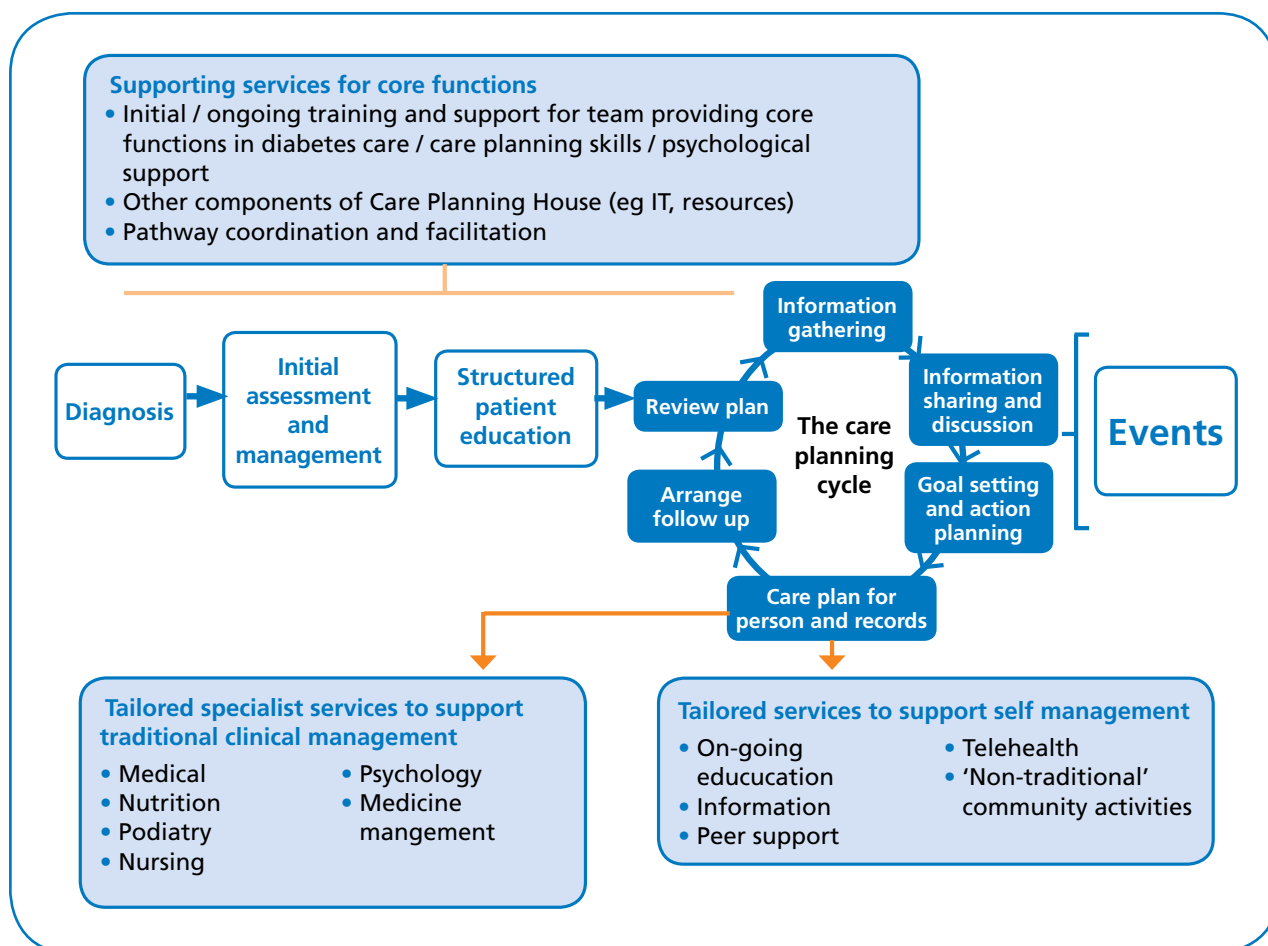
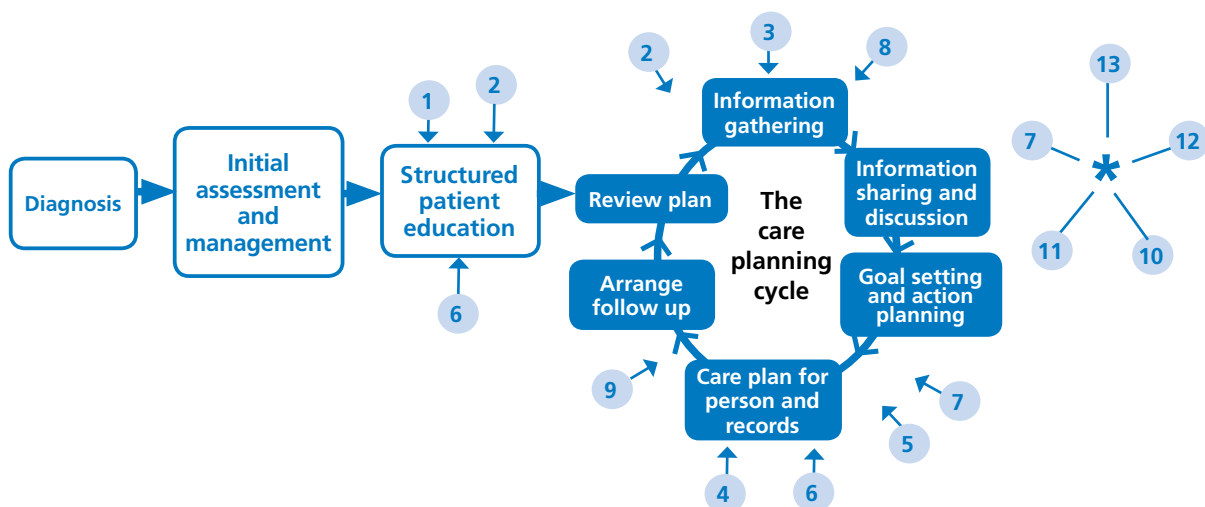


Figure 38 demonstrates that specialist teams have an important role in ensuring that everyone involved in care planning is adequately trained to do so, has easy access to specialist support and that specialist services are part of tailored packages of care arising from the care planning encounter. While a care planning approach addresses the gap in services to supported self management (SSM), which is the focus of the YOC project, it includes the traditional function of surveillance and identification of issues where early specialist intervention is important.

With the publication of the NICE National Quality Standard for Diabetes in March 2011¹¹⁹, Figure 39 demonstrates that nine of the 13 standards can be delivered directly as part of the YOC model, with economies of scale for the commissioner and truly integrated care for the individual.

119 National Institute for Health and Clinical Excellence (NICE). (2011). *Diabetes in Adults Quality Standard*. (Online) Available from www.nice.org.uk/guidance/qualitystandards/diabetesinadults/diabetesinadultsqualitystandard.jsp

Figure 39: The delivery points in the diabetes intervention map for National Quality Standards in diabetes



Topic of each standard

- | | |
|---|---|
| 1. Structured education | 8. Assessment of risk and complications |
| 2. Advice on nutrition and physical activity | 9. Psychological issues |
| 3. Annual care planning | 10. High risk feet |
| 4. HbA1c target | 11. In patient care |
| 5. Medications according to NICE guidance | 12. Ketoacidosis |
| 6. Insulin initiation within structured programme | 13. Hypoglycaemia |
| 7. Pregnancy and pre pregnancy | |

* Standards delivered in specialist settings (head of the 'tadpole diagram')

Chapter 16: The Year of Care commissioning model for long term conditions

This chapter describes a new commissioning framework for services for people with long term conditions (LTCs) and describes how Year of Care (YOC) pilots have developed and used it.

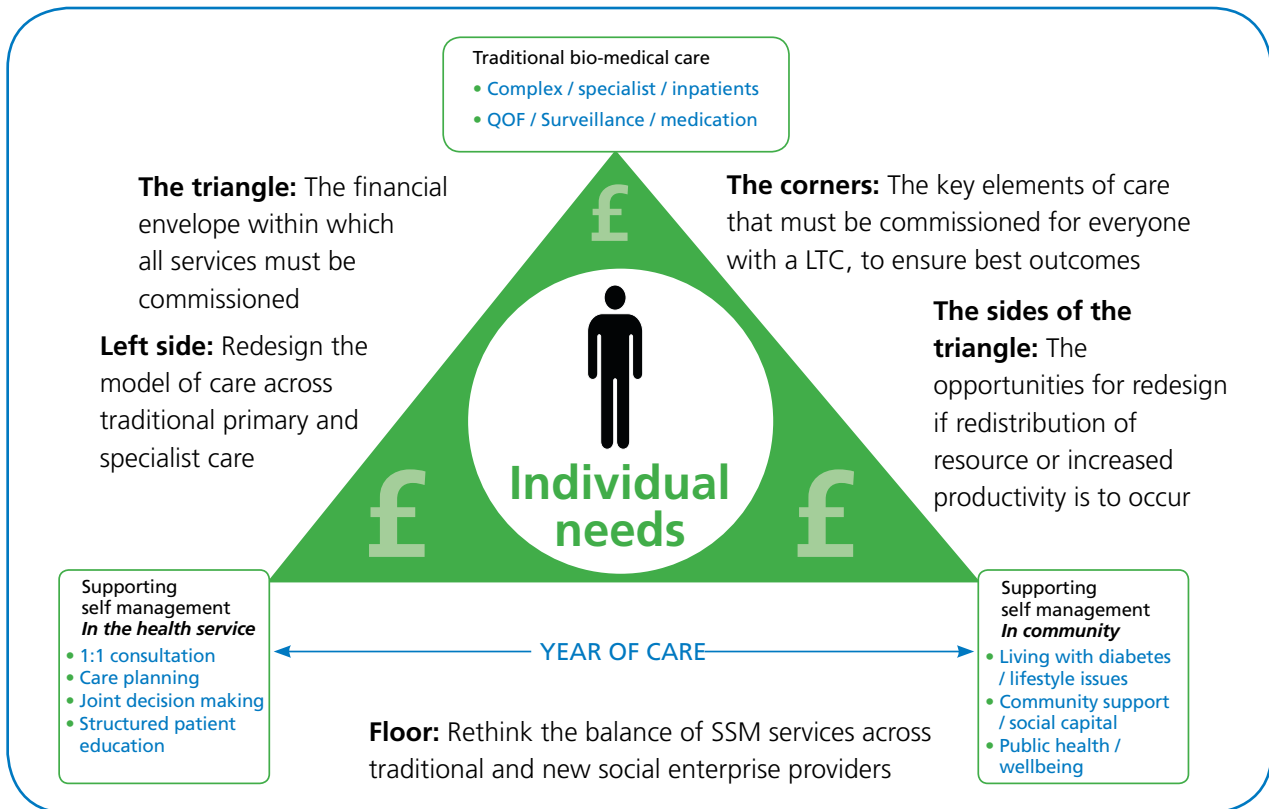
Key points

- YOC has articulated a new commissioning framework for people with LTCs.
- Using this framework, YOC sites were able to identify real and potential shifts in resources to support large scale improvement in productivity.
- Some of the structural and commissioning barriers to integrated provision of care across the whole health economy for people with LTCs such as diabetes are discussed.
- The YOC pilot sites suggest that this approach is tested as part of the new commissioning arrangements.

The previous chapter demonstrated the interdependence of the components of a traditional diabetes service based on care planning. The YOC pilots were charged with delivering both personalised care planning in routine practice and new 'non-traditional' services to support self management (SSM). To do this, they needed to rethink the principles and practice of service redesign across the whole local health economy as they tackled the issue of how this could be resourced at a time of diminishing funds (Appendix 7: Year of Care Commissioning Summary). The outcome was a model which addresses these issues as an exemplar for other LTCs. This model, in Figure 40, describes the components of care from a functional rather than an organisational perspective. The commissioner is challenged to think about spending a finite resource on the basis of three broad categories of care – traditional biomedical care, care to support self management within the institutional health service, and care to support self management in the wider community or at home. This is instead of considering only the traditional health service organisations within secondary, primary and 'community' care.

This not only throws the decisions that need to be made into sharper focus for both the clinician and the finance director, but opens up a much wider range of solutions during the process of service redesign. It also gives greater legitimacy to the claims for other important services supporting self management, during those discussions.

Figure 40: The YOC Commissioning Model for LTCs



Currently in most health economies the majority of resource devoted to long term condition management is tied up in traditional biomedical interventions, whether they be in primary (QOF, medication use, disease surveillance) or specialist care (management of complications, routine outpatient visits, etc).

Whilst the traditional argument that SSM can save money, especially in the long term, was a powerful lever for the YOC programme itself, the pilot sites found that the YOC approach could stimulate different and potentially greater economies across the whole health economy. The services to SSM are relatively cheap in themselves and care planning can be almost cost neutral in the long term (Chapter 9). However, the stimulus that care planning provides to redesign diabetes services around the clinical encounter, may indirectly increase short term productivity across the whole pathway.

Real and potential shifts in resources

Using detailed understanding of local implications and costs, YOC sites were able to identify real and potential shifts in resources to support large scale improvement in productivity. Examples of increased productivity across four levels of local commissioning activities are described below.

Unit costs (Figure 40, right side of triangle)

- Compare costs of traditional weight loss referral to a specialist dietitian (£21.25 per hour), with an action plan developed with a qualified health trainer (£11.45 per hour) who uses knowledge of the range of local community resources to help the person choose an individual approach to ongoing support. The specialist dietitian while continuing to see relevant referrals has an important role in training the health trainer and ensuring there are links into the specialist service.
- Compare the cost of attendance at a DESMOND course with benefits sustained over 2–3 years (£75) with the cost of the newer NICE recommended drugs to reduce blood glucose in Type 2 diabetes (£35 for two months) (left side of the triangle).

Redesign of primary care ‘packages’ (the floor of the triangle): NHS Tower Hamlets configured all practices into eight *Health and Wellbeing* clusters linking Primary Care with Public Health, based on care

planning for all (Chapter 14) (base of the triangle). As new care pathways to follow up goals and action plans are redesigned around non-traditional providers (NTPs) (Chapter 13), resources can be used differently and flexibly within these increasingly integrated organisations.

Reduction in costs of improvement plans: The experience of NHS Kirklees as they redesigned their QIPP-based improvement plan is particularly interesting, as it is based on a new understanding of both the needs of people with diabetes and the role of primary, as well as specialist, care. After involvement in the YOC programme they recognised the centrality of care planning to the provision of routine services (Chapter 15) and they reconfigured their improvement programme to take this into account. Figure 41 shows their cost estimate for the improvement programme before involvement in YOC (£452,000 across two years) as compared with after YOC (£148,000 across three years).

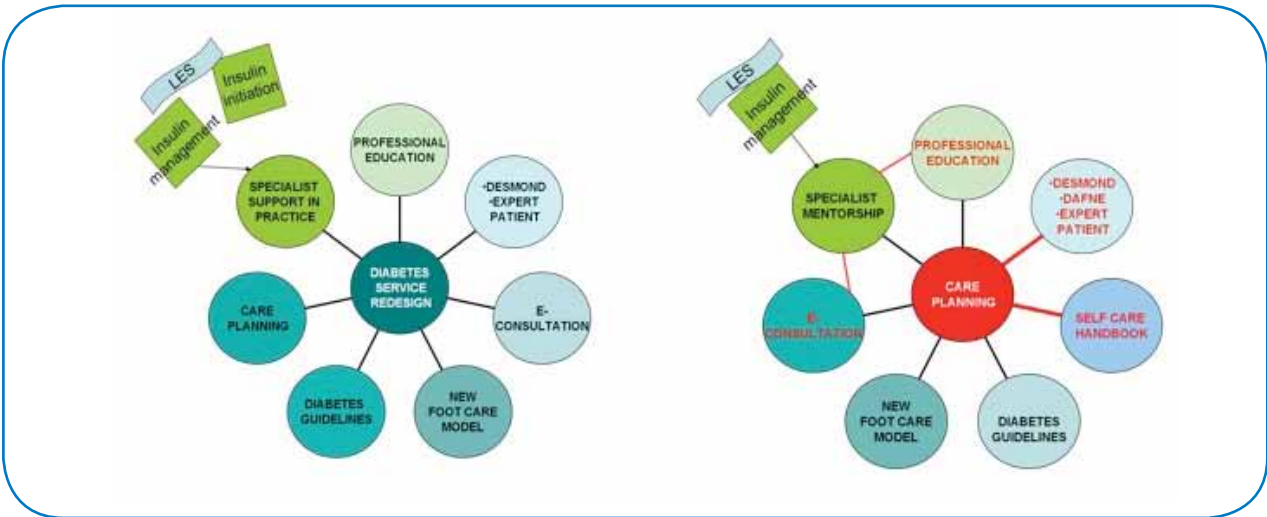
Figure 41: Kirklees the predicted costs of their improvement plan for diabetes before and after involvement in YOC

Business case for diabetes service	2010–2011	2011–2012	2012–2013
Before Year of Care	265,889	185,898	0
After Year of Care	15,893	78,483	53,736

The plan to improve poor diabetes outcomes in Kirklees prior to YOC was focussed on a specialist-based support programme in which the local specialists worked with individual practices to increase their skills in traditional specialist aspects of care of which insulin initiation was most clearly defined ie moving a specialist function from one site to another, with the local training programme focussed around the biomedical interventions that all people with diabetes need.

As training with YOC proceeded practices became clear that they would need a different set of skills to support people with diabetes through the care planning process. The skills analysis identified a different balance of competencies, which still included an understanding of the biomedical aspect of diabetes care, but which included insulin management rather than insulin initiation alone. Training to fill the specific gaps identified by this needs assessment was not only more relevant but also cheaper, and was based on a package of input for groups of practices from the local diabetes specialists as well as ongoing facilitation at practice level from the individuals who were now quality assured care planning trainers.

Figure 42: Kirklees redesign of diabetes services with care planning driving a cheaper functional model



Reutilising a whole Programme Budget (right side of triangle): NHS North of Tyne was able to perform a detailed Programme Budget and Marginal Analysis (PBMA) across the three health economies they served comparing costs and outcomes with national benchmarks and local service models. This included a majority of the spend at the apex and bottom left hand corner of triangle; that is between traditional biomedical functions and the new health service functions to SSM, such as structured education. This identified £1.4 million being spent across the three localities which could be used to reinvest in a redesigned, patient-centred model of care focused on SSM.

Structural and commissioning barriers

However none of the pilot sites found this has been easy, because of current structural and commissioning barriers. For instance:

- **Top corner – Traditional biomedical care:** The current incentives encourage traditional service delivery by acute trusts to treat patients with LTCs as if they had acute illnesses, and encourage more specialist care instead of more community and self care (Chapter 14). There is no incentive to redesign consultant job plans or multidisciplinary teams while there is no coherent model for LTCs that traditional providers can relate to, or see a role for themselves. The YOC model would demonstrate both a rebalancing and a better role fit.
- **Bottom left hand corner – Supporting self management in the NHS:** There are currently no incentives in the system for culture change; to encourage clinicians to adopt new attitudes and ways of working to support people with LTCs to live effectively with their condition; by coaching and enabling, rather than by advising and prescribing (Chapter 14). The introduction of CQUIN¹²⁰ has affected behaviour change across a range of NHS contracts with acute providers and community providers. However, GMS is currently the only contract in the NHS for which there is no CQUIN enhancement, and primary care outcomes are measured and rewarded through QOF. Influencing the GP contract at a national level could utilise a CQUIN approach to introduce care planning with great benefit, gradually introducing it for everyone via national development milestones.
- **Bottom right hand corner – Supporting self management in the community:** These services are fragmented and extremely poorly understood (indeed not seen as ‘therapeutic’ by clinicians) (Chapter 13). Means must be introduced to link non-traditional providers in the third sector with practice and other clinicians, and to use the opportunities provided by the Health and Wellbeing Boards to address this area systematically.

Moving forward into new commissioning arrangements

This approach needs testing as part of the new commissioning arrangements, recognising the importance of integrating primary, specialist, community and non-traditional care services to deliver bio-medical, self management support in primary care and in the community more effectively, as represented in Figure 40. This is particularly relevant to those areas which are considering a move towards care planning and more support for self management for people with LTCs. Tackling the challenges facing society and the NHS of increasing prevalence of diabetes, and other LTCs, requires re-design of the traditional healthcare system to improve integration between service providers, along with a focus on primary and secondary prevention, so that people with LTCs have access to the appropriate tools, skills, information and advice to be more in control of their own health.¹²¹

120 www.institute.nhs.uk/world_class_commissioning/pct_portal/cquin.html

121 Diabetes UK. (2009). *Improving Supported Self Management for people with diabetes*

Chapter 17: The way we did things

This chapter identifies 10 challenges posed by the stakeholder evaluator for delivering a complex intervention involving cultural change into the complex environment of the NHS.

Key points

Introducing a complex intervention like Year of Care (YOC) into a complex environment is bound to be challenging. Here are ten of those which had to be grappled with:

- Genuine change versus influence through policy.
- Local ownership of the model versus effectiveness.
- Team approach versus central leadership.
- Conceptual approach versus constancy.
- Spread of message versus integrity.
- Solution focus versus problem focus.
- Ability to reshape versus clarity of aims.
- Experiential approach versus preparedness.
- Formal evaluation versus more novel approach.
- Adequate funding at outset versus incremental options.

Cultural change is a key priority for the NHS to improve relationships between people with diabetes and clinicians, and bring about greater personalisation, choice and control and improved integration of services across the health (and social) care system.¹²² All are essential to improve productivity and quality. Achieving this depends on changing the culture of established interactions between clinicians and people with diabetes and between healthcare staff based in different organisations.¹²³

There is a strong evidence base that shifting attitudes and work patterns across such a 'complex adaptive system' can only be achieved through integration and collaboration between stakeholders to align goals through relationships.¹²⁴

Partners in the YOC project were aware that to deliver the complex intervention of care planning designed to change relationships, the Electronic Health Record (EHR) and the care processes through commissioning, a different approach to delivery would need to be adopted from the traditional, and perhaps more structured project management approaches or from a linear sequence of activities. The project applied both project management and change management principles combining these with iterative learning to deliver a structured programme to impact on attitudes and relationships. The focus of this was to improve the care system by changing the patterns of relationships and attitudes of those working in it and those accessing care within it.¹²⁵

The third and final wave of stakeholder research (late 2010), generated insight into the way the project had worked. The research focus was '*Introducing a complex intervention into a complex environment*'. The report¹²⁶ highlighted 10 challenges, or dilemmas, as a way of conceptualising central underlying themes with which YOC had to grapple, and the non-linear approaches that led to the successful outcomes of the project. It is extremely

122 Department of Health. (2010). *Equity and Excellence: Liberating the NHS*

123 Schein EH. (2004). *Organizational Culture and Leadership*. USA: John Wiley & Sons

124 Bate P, Mendel P, Robert G. (2008). *Organizing for Quality*. The Nuffield Trust

125 Griffin D and Stacey R. (2005). *Complexity and the Experience of Leading Organizations*

126 Duquemin, A. (2011). *Year of Care: Reflections on introducing a Complex Intervention into a Complex Environment*

helpful learning that should inform implementation and evaluation of such complex interventions within the complex healthcare environment in future.

Ten challenges

The 10 challenges identified reflect dilemmas experienced as the project applied the three qualities that best characterise YOC: decentralised leadership; conceptual, ethos-driven approach; and iterative development. These were the very qualities that supported the effectiveness of the programme, yet each brought with them very real threats of project derailment or failure. While aspects of these qualities can be tidily packaged in terms well-rehearsed in change management literature (eg empowerment, bottom-up, spread) the reality of their application is challenging and often confusing. As a larger report¹²⁷ reflecting YOC stakeholder views describes these were the very qualities that supported the effectiveness of the programme, yet each brought with them very real threats of project derailment or failure.

Decentralised control

1. Genuine change versus influence through policy

“...it has been a fascinating learning process and probably has made me see that actually, writing policy documents doesn't make a blind bit of difference... unless you actually put someone there, or something in, to actually make it happen at a local level, it just won't. And it doesn't necessarily have to be us that makes it happen, but we have to work out a way of working with stakeholders, to make it happen. And if you do that, you lose a certain amount of control and so that's the give and take.”

Stakeholder interview, 2010

Leadership for the development of the YOC concept was left in the hands of the pilot sites. The central team initiated development by presenting pilot sites with five questions to explore and address, then facilitated opportunities for learning with other sites. The associated challenge is that those who initiated the project were no longer in control of the way it developed.

2. Local ownership of the model versus effectiveness

“So there is this continual paradox that when it's done according to the method... we have worked together to work out how to do it, so that it's successful and so that it's motivating and so that it works. And we can say that when it's done that way, it is motivating and then it works. But when it's not done that way, it doesn't motivate and it doesn't work and it sort of atrophies and therefore the challenge is to keep it on course without of course, controlling it because the thing that's motivating, is that it's about real people working in a really flexible way.”

Stakeholder interview, 2010

A complex model works in situ when it is owned and adapted for its setting. YOC was perceived as an ethos rather than a process incorporating a focus on attitudes as well as facts and structures. The challenge, however, is how to contain the extent to which it changes and departs from its central ethos, leading to loss of impact.

3. Team approach versus central leadership

“I sort of did wonder sometimes initially if the central team was holding that power and perhaps not always sharing everything. But as time's gone on, there has been that mutually working together and that sharing, so I think it's just building that rapport really... you just build that rapport all the time.”

Stakeholder interview, 2010

127 Duquemin, A. (2011). *Year of Care: Reflections on Introducing a Complex Intervention into a Complex Environment*

While development of the YOC concept was always a team effort, governance of the project moved increasingly towards a shared approach as the project progressed. Intentions, at central level, to share governance are nevertheless balanced against the unavoidable final responsibility and inevitable power that rests with the central team.

Conceptual, ethos-drive approach

4. Conceptual approach versus constancy

“... but I think it needs a hook and that’s why we have to keep hooking it onto Year of Care at the moment. And we do need to keep reinforcing it, because it is, you know, it is quite a big difficult step... So it is a huge cultural change.”

Stakeholder interview, 2010

The effectiveness of the YOC approach relies on integrity of interpretation; mis-application of the approach risks bringing disrepute to the programme as it threatens its effectiveness. As a conceptual programme YOC faces challenges in conveying and maintaining the essence of its message. The programme, throughout its three years, developed ‘hooks’ that captured and conveyed the essence of the concept. Hooks included diagrammatic models (such as the House model), real-life examples (verbal and recorded), systematic procedures (sending out results) and the YOC care planning training programme.

5. Spread of message versus integrity

“... anybody can still call themselves Year of Care and use the logo and everything, so there’s still some vulnerability there... one of the ways of doing it would be to have key people who give, key front people, who give the same messages out all of the time, where they are, so that the message is not diluted. You can’t help it getting diluted once it gets past them, but if you have key front people having a consistent message and then working closely with other organisations, the chances of it getting diluted lots are less.”

Stakeholder interview, 2010

As with any programme that believes it has a message of value, YOC aimed to spread its approach to new sites and practices. The challenge, particularly for a programme that has a strong conceptual element, is how to avoid the effect of ‘Chinese whispers’ as the message travels further from its source. YOC has addressed the challenge of integrity by ensuring that people in key positions new to YOC hear the message directly from someone in the central team. This, however, mitigates against fast and far spread.

Iterative development

6. Solution focus versus problem focus

“... it wasn’t that I particularly was sold on the idea of whether care planning could or couldn’t do this... I think it was just that sense of that there was actually quite a lot of congruence between the areas that we were struggling with and then this coming along as a new idea that we could see would fit, if we could make it happen.”

Stakeholder interview, 2010

YOC began as a concept that sites were invited to develop, through exploring five open questions. At that initial stage, with no concrete programme to offer, what was it that persuaded sites to participate? The first sites to engage with YOC were attracted, not by a description of a solution, but by the promise of an intervention that addressed needs with which they identified. When sites began to promote the programme to individual practices they first described YOC as a totally new approach, but on reflection, recognised the importance of working to find resonance between needs each practice acknowledged and the way YOC worked. The challenge comes when working with new, under-explored areas, as was the case with commissioning, where problems or gaps are not well defined and therefore not acknowledged. In the absence of identified problems how does one find resonance?

7. Ability to reshape versus clarity of aims

“... one of the challenges for this project is that it’s not tangible and everybody brought to it their own perspectives of what they thought could or should be happening. And although there was some work undertaken in the initial phases about defining it tightly, they’re still quite broad.”

Stakeholder interview, 2010

The collaborative, experiential and conceptual aspects of YOC all contributed to its characteristic of being an empirically based approach that sites could apply and shape, with development and refinement continuing throughout the project. The flexibility also allowed re-framing of the concept to demonstrate its alignment with changing policy priorities. The challenge, however, comes with evaluation and external expectations. Without clear and explicit messages about what is expected from the project and how success will be demonstrated external stakeholders adopt unrealistic and simplistic expectations that risk disappointment and discredit to the project when it fails to meet them.

8. Experiential approach versus preparedness

“... a lot of the practices have said, well when we started we didn’t know what we were supposed to be doing, and they’d had some training but the training wasn’t really very integrated and didn’t in itself, the trainer wasn’t fully understanding what Year of Care was asking people to do. So I think a lot of people were trying to implement something they were very unclear about what it was...”

Stakeholder interview, 2010

As an empirically based developmental project it was not possible to develop resources for YOC in advance. Training and tools used for introducing the approach to the first practices that adopted YOC were new and experimental. Those introducing the programme felt under prepared. Possibly implementation started too early; possibly the first phase of introducing a new concept will always feel too early. The challenge is that the first sites to receive YOC were often the most enthused yet received the least developed introduction to the programme.

9. Formal evaluation versus more novel approach

“I probably would have had a gap in the middle [of the evaluation] to actually give a couple of years to really embed this, although the risk of doing that is that when you go back in two years time, nobody is doing anything... [wait] two years and then go back for evaluation... So we could have done that, or just set up a separate programme to have reviewed it two years later.”

Stakeholder interview, 2010

As a funded project YOC was subject to the usual expectations of formal evaluation with standard requirements for data collection and analysis to coincide with the end of the project. As an iterative and conceptual programme the standard evaluation model did not fit well with the real experience of those implementing YOC, resulting in frustration and disappointment in the sites and practices. The challenge is to find alternative and more flexible approaches to evaluation.

10. Adequate funding at outset versus incremental options

“Because we’ve got some external funding from our SHA, we’ve got a separate arm of the project that’s...”

Stakeholder interview, 2010

Starting as it did, with an iterative approach to development; it would have been difficult for YOC to predict the expenditure required at the outset. Despite its initially restricted funding it was able to develop two components (the training programme and commissioning models) that proved central to the programme’s success, once it was able to access two sets of external funding. On the other hand, a third component of the programme that would ideally have been devised while the programme was in progress (IT programmes) were delayed due to inability to fund their development. Is it more realistic, rather than demanding estimates of required funding at the outset, instead to provide limited funding at the start, and then enable reasonable access to additional funding as needs emerge?

Chapter 18: Answering the six project questions

This chapter summarises the learning identified to answer the six project questions the programme set out to answer, including implications for policy and concluding with a word about the future.

Key points

- The Year of Care (YOC) pilot of the programme has answered the six 'project questions' set at the start to the project.
- It has developed practical support for the three components of the YOC approach, namely care planning, non-traditional provider development and the Information Technology (IT) to link these aspects.
- No site was able to implement all components of the YOC approach simultaneously and link them in practice during the timescale of the pilot programme.
- This work will be completed by three commissioning consortia in North of Tyne using NHS North East HIEC funds over the next 12 months.
- The YOC Programme is also exploring how to develop a community of practice to share new learning, and involve local trainers in the further development of the Training and Support Programme.

The YOC Partnership Board set 'six project questions' to answer at the beginning of the project. These were:

- How to establish care planning in routine use?
- How to identify sections of the local population by potential need for services to support self management?
- How to systematically link individual choices / actual service use into population level commissioning?
- How to develop new and existing providers to support self management?
- What are the routine care costs before and after the YOC approach?
- What does it mean for policy?

Answers to all these questions have been provided within a three year timescale. Opportunities and challenges were many, both in the delivery of care planning as a complex intervention aiming to change how people with diabetes and healthcare professionals relate, as well as in the linking these goals and actions to inform commissioning of quality services within local healthcare systems.

How to establish care planning in routine use

Care planning is now the norm for people with diabetes across the three very diverse YOC pilot sites (Chapter 9). It is being introduced systematically into 12 other health communities and is being extended to people with long term conditions (LTCs) other than diabetes (Chapter 8).

Success depends on changes in professional attitudes and skills, and changes in infrastructure being introduced together (Chapter 5). A supportive commissioning context (Chapter 10) which includes engagement of people with diabetes (Chapter 11) and redesign of clinical pathways across the health community (Chapter 15 and 16) with grass roots support at practice level (Chapter 5), is needed to deliver change.

The YOC pilot phase of the programme has identified the practical steps which lie behind each of these complex concepts and packaged them together in a tested National Training and Support Programme (Chapter 7).

This supports a health community systematically through the steps leading to successful implementation.

Working directly with, and via, a quality assured 'Training the Trainers' package the team have trained 1,000 practitioners and 40 (soon to be 60) quality assured trainers across England.

The package of training and support includes: the rationale and case for change; the clinical consultation model; an organisational model (the House); the training package (modules for clinicians, practice managers, healthcare assistants and community staff); resources for start up and local adaptation to guide steering groups and facilitators; practical guidance on IT; and suggested metrics and indicators. These are available for quality assured trainers to use.

The practical tips for introducing care planning include:

- high level organisational support, including a steering group
'right from the top, right from the start, right the way through'
- leadership (managerial and clinical) which must include GPs (Chapter 5)
- linking to the local commissioning agenda (Chapter 10/14)
- having clarity about purpose and process (Chapter 5)
- identifying care planning within the local model for delivering diabetes care (Chapter 15)
- identification of support and resource for reorganisation if required
- project management with a responsible project manager/coordinator/facilitator roles identified (Chapter 5)
- training and ongoing support (Chapter 7)
- information Technology systems (Chapter 6)
- identifying metrics for monitoring, measurement and improvement (Chapter 6).

Each of these elements must be linked via a common philosophy, language and strategy.

How to identify sections of the local population by potential need for services?

The YOC pilots used a variety of different systematic and informal approaches to assess local need (Chapter 12). The most effective were locally developed, targeted specifically at the characteristics of the local population, taking place in familiar venues and facilitated by local staff. Local engagement was strongest where publicity remained high throughout the duration of the pilot phase of the programme and the introduction of changes in response to consultation raised awareness still further (Chapters 6 and 11).

Social marketing techniques were able to stratify the local population of people with diabetes into various subgroups depending on the way they were perceived, or perceived themselves, as managing their diabetes. This proved instructive for staff. There were concerns about labelling individuals, but beyond verifying the need for better support for self management tailored to individual need and indicating that people needed a variety of education packages to engage, this did not lead to practical action (Chapter 12). If better means of commissioning new services had been available earlier in the pilot phase this might have been more successful.

In Tower Hamlets routine clinical data was successfully used to stratify people into groups with different levels of clinical complexity and this became the basis for commissioning new 'packages of care'.

How to link systematically individual choices / service use into population level commissioning?

The care planning process successfully identifies individuals' goals for management and action plans to support this. Increasingly these are related to self management (Chapter 6). It is possible, but uncomfortable, to carry out care planning without IT support, but specific IT solutions are required to capture and report on goals, action plans and unmet need if these are to be systematically fed into commissioning. YOC worked with software designers and suppliers of primary care IT systems to specify, and begin to test, the appropriate fields and datasets to enable this to happen. This is now available on some systems but not yet all and will be a key aspect of the next phase of the YOC programme.

How to develop new and existing providers to support self management?

Following a survey of English health communities it became clear that very few areas, if any, had a systematic approach to developing and commissioning third sector organisations. The role such organisations play is an important part in delivering local tailored services at the heart of community support for healthy life styles and YOC carried out a specific piece of work to address this (Chapter 13). The pilot sites had found this challenging. Although sites were able to increase the provision of such services during the duration of the pilot programme phase and raise awareness of them within their communities via directories, these remained fragmented and largely based on historical provision.

North of Tyne built on the experience of the YOC Programme and a successful model of a lead third sector organisation, working closely with primary care and other local non-traditional providers in a neighbouring health community. They successfully sought NHS North East Innovation funds to produce a Guide to support commissioners in developing and procuring such services using a lead provider model. This project completed after the formal end of the pilot phase of the YOC programme and, this model will now be used by three commissioning consortia in North of Tyne to test implementation and the practical links with the commissioning aspect of the YOC approach in the next phase of the programme.

What are the routine care costs before and after the YOC approach?

The plan to use people with diabetes who had received care planning and volunteered to report on their use of services before and after becoming involved in care planning was unsuccessful. This was because of the limitations of the questionnaire used. In any case it would not have been possible to draw meaningful conclusions about the use of hospital services from the small number of people who had been through more than one care planning cycle. Currently electronic systems are not set up to record the total contact time an individual has with a practice including telephone calls and appointments with the different members of the practice team. Anecdotally healthcare professionals felt that the increased time spent on the two care planning visits was offset by reduced contact over the rest of the year, except in Tower Hamlets where packages of care specified certain ongoing contact as part of each of the four packages.

It was possible to identify detailed and comparative costs of care planning within each practice based on people with diabetes' contact time with staff involved in the care planning pathways before and after the introduction of care planning (Chapter 9). While this demonstrated enormous variation between practices both before, and in response to an almost standard care planning specification, making direct comparisons impossible, the overall staff costs including increased administrative time were broadly cost neutral. Because of these variations, commissioners will need to make a local assessment before introducing new payment systems, and the framework used by YOC to clarify working arrangements at practice level might prove useful as one component of this audit.

What does it mean for policy?

YOC was set up to identify how key policy objectives could be implemented in practice. Having succeeded in this it is important to summarise the learning that might influence further policy development.

The drive for personalisation and a more patient centred and responsive health service needs to be based on, and driven by, the lived experiences of those using the service and the healthcare professionals working within it. National standards and indicators provide an essential framework in which to encourage and sustain improvement, by identifying poor practice and outliers, but cannot replace the importance of improving processes and relationships as the main impetus for action. Commissioning, service redesign and the metrics to support improvement, needs to support and be based around these relationships rather than designed in isolation.

Supported self management (SSM) is fundamentally about addressing the power imbalance between the person with diabetes, or other long term conditions (LTCs), and the healthcare professional. The tailored training and support needed to deliver care planning makes it a powerful lever for changing attitudes and their consequent behaviours for professionals, people with LTCs and potentially other service users who may benefit from the cultural change that occurs.

The focus on relationships and partnership with people who use the service, as the driver to improve them, improves job satisfaction and productivity within the workforce.

The YOC model for commissioning LTCs provides a new lens through which to view the commissioning and provision of services for people with LTCs such as diabetes, and enables local and flexible commissioning across the whole health system. As such it provides an alternative approach to support the policy of strengthening services for people with LTCs which could be tested within the new commissioning arrangements. Introducing care planning is as important as the Quality and Outcomes Framework and there is potential that this can support its delivery.

Identifying and actively supporting the IT requirements of 'no decision about me without me' is important. This is likely to be more effective in supporting cultural and systems change if it is both designed around, and designed to support, the new ways of working described here, rather than shape them.

There are opportunities for much greater development of third sector and other providers of services to support self management, but this will need greater attention to the reality of how these are organised and operate.

Conclusion

As well as addressing these six project questions, one of the most valuable outcomes of the pilot phase of the programme has been the learning accumulated about the components and processes which support delivery, including the detail, dilemmas and issues for further development and debate. This has been invaluable to the pilots and is the rationale for its inclusion in this final report.

Despite these successes, sites were unable to implement all components of the YOC approach simultaneously and link them in practice during the timescales of the project. This was in large part due to the late solution to the IT challenges, but also due to the unexpected lack of NHS experience and skills in commissioning non-traditional providers in a systematic way.

Far from accepting that care planning and commissioning cannot be linked, there is strong commitment to achieving this at all sites which have each developed plans for embedding and sustaining care planning, despite financial pressures. There are real fears that key components for delivering this new approach to increasing patient choice and control over their own health and healthcare, such as the essential coordination and facilitation functions will be lost, which would undermine the benefits of this new approach to clinical care.

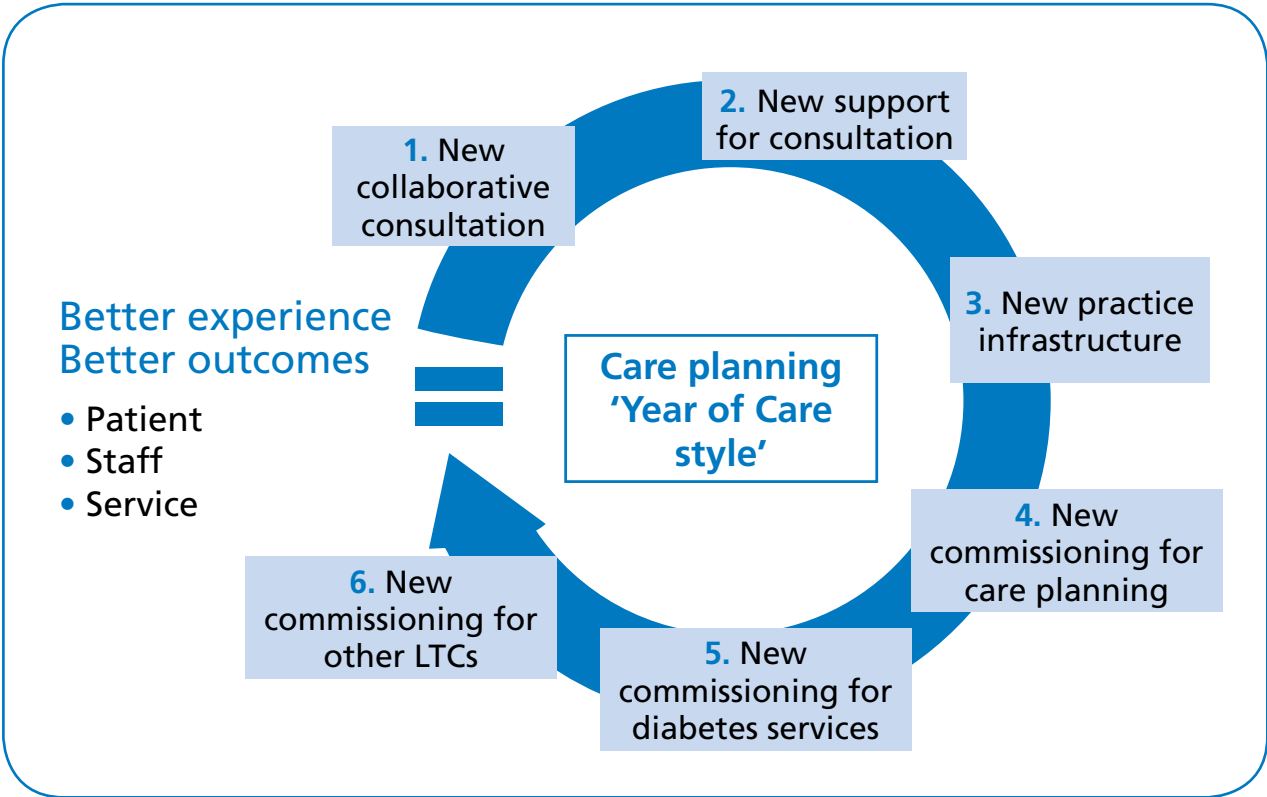
The pilot phase of the YOC Programme has completed, but the programme goes on. Care planning is embedded in the commissioning arrangements at all three pilot sites which intend to join a YOC community of practice to spread new learning. This will increasingly be developed across a much wider range of health

communities and the increasing expertise of local trainers can be incorporated in the developing Training and Support Programme. Three clinical commissioning groups in North of Tyne have received funding from the NHS North East HIEC programme to specifically link all three YOC components prior to rolling out the integrated programme across the North of Tyne area.

End note

YOC started out with the intention of using the systems and structures of health reform to incentivise and lead to a more patient centred service. In the end this was turned on its head. Starting with the development of a new relationship with people with diabetes within the clinical encounter, this resulted in profound changes in how care processes were organised across the local healthcare system; changes owned and valued by the staff who worked within the NHS, as well as those people with diabetes using the NHS.

Recognising this new way of working to support people to have greater control over their lives resulted in staff having a greater say in the sort of health service they worked in.



Appendix 1: Diabetes Year of Care project – summary of evaluation plan

Measure	Purpose	Time points
Primary Care Resources & Supports for Chronic Disease Self Management (PCRS)	A self assessment, feedback and quality improvement tool for use in primary care settings.	Baseline 12 months 24 months
Healthcare Commission Survey (HCC)	To assess whether patients are receiving the care, treatment and information they need from their local services to manage their diabetes.	Baseline 12 months 24 months
Consultation Quality Index (CQI)	To explore the patients personal experience of the consultation (structure, process and outcome). Can also be utilised as a professional development tool.	Baseline 12 months 24 months
Diabetes Treatment Satisfaction Questionnaire (DTSQ)	To identify the patients satisfaction with overall diabetes treatment.	
Quality of Life (EQ-5D)	A measure of health outcome, providing a single index value for health status. A short 5-item instrument.	
Hot Topics (optional)	An additional facility to allow patients to feedback comments, observations and suggestions about their care and the services that provide it.	Offered at: Baseline 12 months 24 months
Biochemical indices	To assess change in key indicators across time.	Baseline 12 months 24 months
Client Services Receipt Inventory (CSRI)	To capture patterns of service receipt, which are used as proxy indicators for costs.	Baseline 12 months 24 months

Appendix 2: Year of Care outcomes framework for care planning

Everyone involved in care planning will want to know they are getting the most benefits or doing a good job. But care planning has many component parts (summarised in the Year of Care (YOC) 'house') all of which are important to achieve good outcomes. Some of these are not easily 'countable' or measurable on a routine basis. So YOC emphasises the importance of developing a 'learning' or 'reflecting' organisation in which routine data fields are set up to record what is important as well as what is easy to measure, and teams develop audit and evaluation 'frameworks' that suit their circumstances and address the particular issues they are reviewing.

Experience during the YOC Programme

A traditional evaluation ran alongside the YOC pilot phase of the programme. This collected large volumes of questionnaire data on service availability, use and satisfaction as well as experience of the clinical encounter and health status.

The lessons learned were that such quantities of data cannot be collected routinely as the volumes overload both the service users and the service itself. Each component also needs to be closely targeted on a particular feature of the care planning process it is trying to assess.

Local targeting collections proved much more useful to the sites in terms of improving their structure, processes and immediate outcomes. For instance interviewing staff and patients immediately after their care planning consultation on the experience of receiving their results gave an early indication of its usefulness; and a facilitated discussion using the PCRS-UK tool enabled practices to reflect on their support for patients and on their internal processes, as well as seeing improvement year on year.

Each pilot site developed slightly different approaches to commissioning care planning using Local Enhanced Service agreements (LES). These contained indicators of structure and process of care planning. Most stipulated key components of the 'internal practice pathway' expected, and set up fields to record test results sent to patients (proxy for receiving them), and the presence of patient goals and action plans within the routine record. Some stipulated that sample care plans should be submitted for peer or other review.

Working with other organisations

The YOC Programme worked with the RCGP to develop a guide to care planning for practitioners *Care Planning – Improving the Lives of People with Long Term Conditions* RCGP (2011). This includes a comprehensive measurement framework and references to the many useful tools available to support all parts of the process.

The aim was for a practice to be able to answer the following questions:

- How will we know how we are doing? How can we do better?
- How can we improve our care planning skills?
- How successful is our practice at enabling people to self manage effectively?
- How can we monitor our attitudes and our processes?

The YOC Programme also contributed to the work at the Department of Health to develop a 'single' measure or set of PROMS that could be used to measure the quality of care for people with long term conditions (LTCs) on a national basis. This work is continuing, but YOC has ensured that the potential national metrics are included here.

The YOC outcomes framework

This learning has been collated in the following framework which is far from comprehensive but includes the key components that the programme identified as being important. It highlights (in red) examples of structure, service monitoring and outcomes from which a service could select, and which could be introduced relatively easily by a clinic or practice as they get going. It includes traditional biomedical outcomes, but with the reminder that improvements in these are unlikely to occur until care planning has been established for 3–5 years. It is important to embed robust and sustainable processes if the long term clinical benefits that the evidence predicts are going to be achieved.

A list with web links, of specific tools, questionnaires and sample competency frameworks etc is provided at www.diabetes.nhs.uk/year_of_care

Glossary of the acronyms used in the framework:

CQI: Consultation Quality Index

PPIC: Patient Partnership in Care

PCRS-UK: Primary Care Resources and Support

PAM: Patient Activation Measure

LTC 6: Long Term Conditions 6

LWYLTC-Patient Survey: Living with your Long Term Condition

HCCQ: Health Care Climate Questionnaire

Questionnaire	What it measures	How to obtain it	Other information
PPiC: Patient Partnership in Care	16 questions to be completed by the patient following an individual consultation It focuses on partnership working and support for self management	Only available under licence but can be viewed from the following sources: Powell, R. Powell, H. Baker, L. & Greco, M. (2009) Patient Partnership in Care: A new instrument for measuring patient-professional partnership in the treatment of long-term conditions. <i>Journal of Management & Marketing in Healthcare</i> . Vol. 2 No. 4. PP 325–342.	This questionnaire would need to be applied and paid for
PCRS-UK: Primary Care Resources and Support	Individual practitioners complete this questionnaire independently. It consists of 16 questions relating to support for self management under patient and organisational headings	Availability for use and instructions for downloading it can be found at: http://diabetespo.im.wustl.edu/support/primaryCare.html	Available free of charge but the site requests you inform them if you plan to utilise this in order to allow them to track its use
EQ5D	EQ-5D™ is a short questionnaire that patients can use to rate their health status	Only available under licence but can be viewed from the following sources: www.euroqol.org/eq-5d/what-is-eq-5d.html	A fee will be charged for use of this questionnaire. This will be calculated after registration and will depend on a number of factors listed on web link
PAM: Patient Activation Measure	This tool can be used to measure patient activation at both an individual patient basis (to diagnose activation and individualise care plans) and to compare the efficacy of interventions such as care planning	Only available under licence but can be viewed from the following sources: Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in patients and consumers. <i>Health Services Research</i> 2004; 39:1005–1026.	This questionnaire would need to be applied and paid for
Long Term Conditions 6 (LTC 6) (part of the QIPP programme)	Six brief tick questions for patients to complete following a consultation covering areas including involvement, support and confidence	Please see website: www.diabetes.nhs.uk/year_of_care	

<p>Living with your Long Term Condition (LWYLTC) Patient Survey</p>	<p>33 tick box questions for patients to complete following a consultation</p> <p>Areas covered include ability to cope, consultation skills of the practitioner from this visit and views on visits over the last 12 months, ability to self care, basic demographics including identification of LTC</p>	<p>Please see website: www.diabetes.nhs.uk/year_of_care</p>	<p>Some of the wording would need to be modified – ie site, who is performing the survey,</p>
<p>CQI-DM (Consultation Quality Index) – version adapted for diabetes</p>	<p>18 tick box questions for patients to complete following a consultation (some of which are extracted into LWYLTC) and therefore cover similar themes</p> <p>Focuses on ability of the patient to cope and self manage with diabetes, and consultation skills related to care planning</p>	<p>Please see website: www.diabetes.nhs.uk/year_of_care</p>	<p>CQI instructions and results template available from the YOC National Programme</p>
<p>Health Care Climate Questionnaire (HCCQ)</p>	<p>15 scaled questions rating the clinicians style of consultation</p>	<p>Please see website: www.diabetes.nhs.uk/year_of_care</p>	

Outcomes framework for care planning for a practice or other clinical team: linking the organisation, clinical behaviour and outcomes.

Component	Service monitoring	Outcome indicators
Structure	*Register of population identified for care planning	*Denominator for service monitoring
	Prepared team (with) *clinical lead	
	*A clinic/ practice care planning 'pathway', with roles identified – and audit framework	*Written evidence, including annual review of staff and practice costs
	Trained staff (new and in post)	*Audit of competencies / training attended
	IT including key components in place	Availability
	Menu of services for Support for Self Management	Availability and up to date
	Practice plan for audit, monitoring, reflection and improvement (Including records and care plans review)	*Available
Process		% of the registered population who...
Preparing for the consultation	Information about new service /new to service provided	Received / understood information
	*Tests results to person with diabetes before CP consultation	*Received results (Results sent out – proxy for a newly developing service)
		Evidence of meaningful reflection on test results
Quality of the consultation	Jointly reviewing person's concerns, priorities and agenda setting	*Systematic recording of goals and action plans in language that implies ownership of person with diabetes
	*Goal setting and action planning	*% who feel supported to manage their condition – clinic exit question (currently in national GP survey: and NHS Outcomes Framework; 2011–2012)
		% completing all or part of CQI or PPIc or LTC 6 or LWYLTc or HCCQ
	Individualised follow up arrangements	Record
After the consultation	*Summary 'care plan' available for the person	* Written summary (care plan)
	Follow up arranged: goals and action plans reviewed	Evidence in records
Overall service		'Patient satisfaction'/'Patient experience' Practice support for self management (PCRS-UK)

* Could be introduced relatively easily

Appendix 3: Using PCRS-UK (Assessment of Primary Care Resources and Support for chronic disease management) – a new tool for support practice self reflection improvement

How good is primary care at supporting self management for people with diabetes?

Using PCRS – UK (Assessment of Primary Care Resources and Support for chronic disease self management) - a new tool to support practice self reflection and improvement

Dr I Hodgkinson¹, Dr S Roberts², Dr D Russell¹, Ms A Worthington¹
¹NHS Tower Hamlets, ² Year of Care Programme Board



Aim

Better support for self management (SSM) is a high priority for people with diabetes, and for today's NHS. We describe the use of a new tool, the PCRS - UK (Primary Care Resources and Supports) designed to map changes in SSM at practice level, during the Year of Care Programme (YOC).

Background

The PCRS¹ is a validated tool for self assessment. It is designed to help primary care teams focus on the actions needed to support self management for people with diabetes and other chronic diseases, and the level to which this is integrated into their practice.

The PCRS is divided into two components - **Patient Support** and **Organisation Support** - each with 8 domains and ratings of 1 –10. The PCRS tool licensers approved two word changes for UK use to produce the PCRS-UK¹.

Figure 1: PCRS-UK domains

Patient Support (PS)		Organisational Support	
PS 1	Assessment of Patient's Self –management educational needs	OS 1	Continuity of Care
PS 2	Patient self –management education	OS 2	Coordination of referrals
PS 3	Goal Setting / Action Planning	OS 3	Ongoing Quality Improvement (QI)
PS 4	Problem - Solving skills	OS 4	System for documentation of self–management support services
PS 5	Emotional Health	OS 5	Patient input
PS 6	Patient Involvement	OS 6	Patient integration of self –management support into primary care
PS 7	Patient social support	OS 7	Patient Care Team (internal to the practice)
PS 8	Linking to Community resources	OS 8	Doctor, team and staff self management education and training

Methods

In one of three national YOC pilot sites, 7 primary care teams completed the PCRS-UK annually for three years (2008-2010) to review and record their readiness to support self care. The feedback from each practice was mapped to the different components of the YOC House. This is a framework for the delivery of care planning, each component representing systems and processes that need to be in place to support a collaborative care planning consultation (Figure 2 middle house).

Figure 2: Centre - The YOC House. Left and right - scores (as Figure 1) for 2 representative practices : A and B



Results

Scores can only be compared within a practice.

Practices reported an improvement in:

- Consultation skills - (range 3.7- 9.0)
- Supporting patient engagement – (range 3.0 – 9.0)
- Organisational processes – (range 3.3 – 9.3)
- Practitioner commitment – (range 4.0 – 9.7)
- Commissioning – (range 5.0 – 9.0)

Three out of the 7 practices dropped a total of four scores in 2009, two recovering by 2010. One score dropped between 2009 and 2010 (9.0 – 8.3)

The changes were congruent with other elements of performance recorded by the local Year of Care team.

Conclusions

PCRS – UK proved a useful improvement tool to enable teams to reflect on their journey as a practice to better SSM for their diabetes population. It also acted as a useful adjunct to discussions during practice visits by the local facilitator, highlighting successes and identifying areas for further support. Some examples of changes which occurred as a result of the YOC Programme are :

- The introduction of robust recall systems
- Improved teamwork
- Improved communication
- Changes in skill mix

PCRS -UK enables changes in practice activity in support for self management to be mapped numerically year by year, supporting self reflection and improvement.

'It was useful to have a discussion about items for which doctors put different scores and about their rationale for their scoring. The examples under various scores were very helpful and generated discussions about what would be ideal care for patients and why it is not always possible to achieve' General practitioner

¹ The Robert Wood Johnson Foundation Initiative, March 2006 : <http://diabetespo.im.wustl.edu/support/primaryCare.html>

Appendix 4: Relevant data from surveys collected by Tribal Consulting and Picker Institute for the Year of Care pilot sites

	North Tyneside				West Northumberland		Calderdale and Kirklees				Tower Hamlets		
	Oct 2008/2009 Whole group	Oct 2009/2010 Those with both years	Oct 2009/2010 Those with both years	Oct 2009/2010 Those with both years	HCC 2006 Whole of Northumberland	2009 West locality only	HCC 2006	Oct 2008/2009 Whole group	Oct 2008/2009 Those with both years	Oct 2009/2010 Whole group	Oct 2009/2010 Those with both years	2006 (40% returns) 50% white	Picker Nov 2009 (26% returns) 46% white
Numbers completing	457				227		2	259	85	157	85	228	
	% response												
HCC (or comparable within Tower Hamlets)													% response
Enough time	81	79						69		64			
Confidence in clinician	90	90						84		86			70
Almost always agree a plan*	60	63			52	78	48	58		61			52(YOC) 44 (nonYOC)
Almost always discuss goals and action plans	58	61			51	72	38	50		52			56
Almost always discuss ideas for managing their diabetes	58	62			56	79	45	56		56			57
Almost always receive blood tests in writing	22	62			15	64	5	62		57			45% received YOC 'pack'
Almost always receive a plan**	33	40			56			11		39			65% of those with a plan with a plan (YOC)
Rarely receive a plan**	50	40						61		42			
Almost always find the plan useful***	79	85						87		74			85
Definitely listened													73
Involved in decisions as much as wanted to be													82
Numbers completing	767	401			259-268			221		119			
Numbers completing both times	54	54									87		
DTSQ	31.8	33.1	31.6	32.7	32.9			30.9	29.9	29.9	29.8		
EQ5D	0.7	0.7	0.7	0.7	0.71			0.73	0.73	0.66	0.66		

*Could be confusion over interpretation as verb or noun ** assumed to be 'written' plan ***this statement refers to the plan that was received in writing not the process of planning

Definitions used in the various surveys for questions relevant to Year of Care (YOC)

The wording in these questionnaires is subtly different in many places and in some might be interpreted in different ways by respondents. The definitions are given here so readers can decide. The best fit has been made in the table above.

YOC Pack

- Q7: Thinking about the last 12 months, when you received care for your diabetes did you... **Discuss your goals** in caring for your diabetes? Rarely: Some of the time: Almost always
- Q7: Thinking about the last 12 months, when you received care for your diabetes did you... **Discuss your ideas** on the best way to manage your diabetes? Rarely: Some of the time: Almost always
- Q7: Thinking about the last 12 months, when you received care for your diabetes did you... **Have enough time** to discuss your condition?
- Q7: Thinking about the last 12 months, when you received care for your diabetes did you... **Plan to manage** your diabetes over the next 12 months? Rarely: Some of the time: Almost always (We are assuming this is the process of agreeing the plan)
- Q7: Thinking about the last 12 months, when you received care for your diabetes did you... Receive **a written copy** of your care plan? Rarely: Some of the time: Almost always (We are assuming that this is the written plan after the consultation)
- Q7: Thinking about the last 12 months, when you received care for your diabetes did you... Has the **care plan helped to** manage your diabetes?
- Q7: Thinking about the last 12 months, when you received care for your diabetes did you... Did you **have confidence** or trust in your doctor or nurse Yes always / Yes sometimes / No
- Q9: In the last 12 months were you **given your test results in writing**? Yes / No / Didn't want results in writing / Don't know (chol/BP/urine tests/blood tests)

2006 HCC Survey

- Q12a: identical with Q7: Thinking about the last 12 months, when you received care for your diabetes did you... Discuss your **ideas** in caring for your diabetes? Rarely : Some of the time : Almost always
- Q12c: identical with Q7:Q7: Thinking about the last 12 months, when you received care for your diabetes did you... Discuss your **goals** in caring for your diabetes? Rarely: Some of the time: Almost always
- Q12G: slightly different : Q12c : identical with Q7 : Thinking about the last 12 months, when you received care for your diabetes did you... Discuss **a plan to manage** your diabetes? Rarely: Some of the time: Almost always
- Q16. Thinking about your most recent HbA1c test, were you given your test results **in writing**? Yes / No / Did not want results in writing / Don't know (also separately asked the same question for urine test/BP/Chol)
- Q67: Thinking about all the care you receive from your GP surgery, not just for diabetes, have you been **involved as much as you wanted to be** in decisions about your care and your treatment. I was involved as much as I wanted to be/ I wanted to be a bit more involved

TH Picker pack November 2009 (response rate 26%)

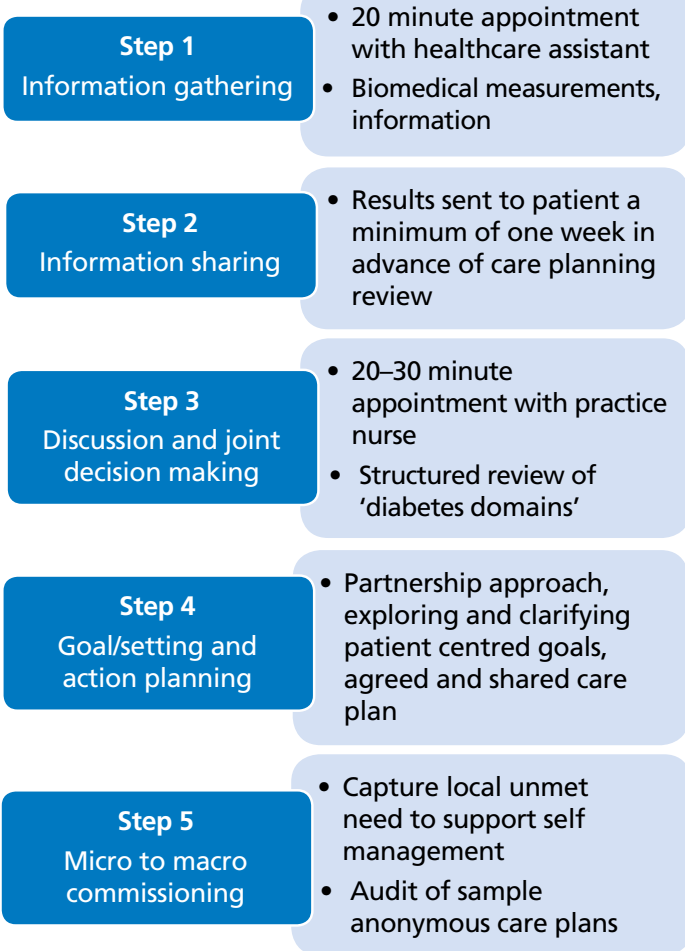
- Q8: Thinking about the diabetes appointments you have had in the last 12 months, did you **discuss your ideas** about the best way to manage your diabetes with the clinic staff? Yes completely / Yes to some extent but not enough / No but I would have liked to / No but I didn't want/need to / Can't remember / Not sure
- Q9: Thinking about the diabetes appointments you have had in the last 12 months, did you feel the **HCP listened carefully** to what you had to say? Yes completely / Yes to some extent but not enough / Can't remember / Not sure
- Q10: During your appointments did you **discuss your goals** for caring for your diabetes? Yes completely/ Yes to some extent but not enough/ No but I would have liked to / No but I didn't want/need to / Can't remember / Not sure
- Q11: Have you and the clinician **set out a care plan** for the best way to manage your diabetes over the next few months? Yes / No / Can't remember / Not applicable
- Q12: Were you **offered a printed or written copy** of your care plan? Yes / No
- Q13: Do you think having a **care plan helps to better manage** your diabetes?
- Q14: Did you have **confidence and trust** in the health professional treating you? Yes definitely / Yes to some extent / No
- Q16: How **involved were you in decisions** about your care and treatment? Too much / About right / Too little / Not sure

Appendix 5: Local LES/LIS* arrangements in place at each pilot site during the Year of Care project

*LES: Local enhanced service LIS: Local Improvement Scheme

A: North of Tyne

A long history of incentivising practices to carry out a well understood structure of routine care existed in **North Tyneside**. New LES stipulated annual care planning to include:



LES: 2009/2011: Replacing a two component LES. Incorporates **care planning** as part of enhanced Diabetes Annual review; all other attendances in primary care are GMS/PMS.



In **West Northumberland** a history of collaborative working across the locally based on Personal Medical Services (PMS) contracts, led to 11/15 practices agreeing to join. They received a one off payment of £1,200 for set up. Also an additional £5 per weighted head of population (registered practice population X practice disease prevalence). Paid in two equal six monthly instalments, on receipt of satisfactory practice reports.

B: Tower Hamlets – the context

During 2008 / 2009, a 'traditional' LES was in place. This aimed to incentivise practices to prepare for care planning by reviewing infrastructure and staff training, experience and competencies.

Following the success of care planning in Year of Care (YOC) practices and the realisation that it provided the basis of care for a wide range, if not all, long term condition management, the PCT built this into their wider work bringing groups of practices together into eight Health and Wellbeing networks. Diabetes services were radically redesigned into tailored **packages of care** (including specialist support) based around individual care planning; distinguished from **pathways** along which the majority of people with a condition are traditionally expected to travel. This was based on stratification of people with diabetes into four groups based on needs assessment and projected resource use. Monitored monthly through a more sophisticated dash board, this became the basis for a new payment structure.

Care planning was expected to become the basis for routine management of people with LTCs, starting with diabetes and currently (2011) including cardiovascular disease.

Tower Hamlets: LES 2008/2009

Register validation exercise

Complete a diabetes service self assessment / create a service development plan for review annually

Set up a new infrastructure to deliver YOC model of care planning (including comprehensive surveillance)

Ensure new model includes written feedback to person with diabetes (anonymous samples to be available on request)

GPs and practice nurses to have training, experience and competencies assessed

Agree to meet PCT diabetes facilitation team

Also:

Uses specified guidelines, patient information and community resources

Patient in audit, professional and practice development

Use patient feedback tool over specified time

- Annual reviews between 50–70% of patients: £20/patient
- Annual reviews > 70% of patients: £25/patients

Tower Hamlets also became part of the national Integrated Care Pilot project. Commissioning of structured participation in multidisciplinary meetings between primary and specialist diabetes team became an important part of the new packages of care. This regular contact was designed to provide speedy specialist oversight for individual people with diabetes, with the potential to avoid referral and travel to specialist clinics, at least as a first step, and up skilling for primary care teams.

LES for 2009/2011

Principles on which package is based

- Effective, systematic patient feedback mechanisms
- Active outreach about services which are available and information that is relevant
- Developing skills to engage patients in service and community engagement
- Same, non exception reported metrics for all patients
- More complex patients to be allocated additional resources
- All new patients to have 14 hours of group education in first year

Minimum requirements of care planning

- Year of care model to replace annual reviews
- First visit for QOF process measures and blood tests
- Patient sent summary of results with appropriate sign posting to information and education
- Followed by a minimum 45 minute annual care planning consultation
- Written summary care plan for patient
- Anonymous outputs captured electronically for commissioning

Multidisciplinary approach: Regular MDT meetings between primary and specialist teams

Newly diagnosed

Newly diagnosed in first six months or newly diagnosed in second six months

- First assessment
- Must refer and encourage attendance at retinal screening and education
- Annual care planning review within three months
- Intensive inputs to achieve biomedical 'control'

Controlled

More than 6 months since diagnosis and all three of the following met
 BP \leq 140/80, HbA1c \leq 7.5
 Cholesterol \leq 4.5mmol

- Annual care planning/surveillance review (20 minutes HCA/30 minutes with nurse)
- Six month review of goals (10 minute HCA/15 minutes with nurse or equivalent – practices encouraged to 'innovate' about style and content)

Off target

More than one year since diagnosis and clinical parameters that exceed any or all of
 BP $>$ 140.80, HbA1c $>$ 7.5
 Cholesterol $>$ 4.5

- Annual care planning/surveillance review
- Three monthly review (10 minute HCA/15 minutes with nurse or equivalent – practices encouraged to 'innovate' about style and content)
- Multidisciplinary case discussions

Complex

Off target and any of the following:
 renal, limb or eye complications
 depression, heart

- Individual 'intensive' input with additional inputs from specialist care and providers

continued from previous

Financial structure: Two components

Protocol Payment: 70%: For undertaking the activity and providing evidence of how spent
Performance payment:

- Stratification recording / coding: 10% (4 steps from 2–10%)
- Patient experience rating (70% completion): 5%
- % with diabetes controlled (30 >50%): 10% (4 steps from 2–10%)
- Care planning (60->90%): 5% (4 steps form 1–5%)

Funding priced against care package: paid to network for network level achievements:
to be spent at choice of network (to practices, for network level support staff, for third
sector support etc).

C: Kirklees

In 2009 the decision was taken to extend care planning to all practices in Kirklees. Because of delay in national training being available or available for sufficient numbers a two stream Local Incentive Scheme (LIS) was introduced for 2009/2010 and then developed further for 2010/2011.

LIS for 2009/2010

Stream A:

GP and practice nurse attends training
Starts delivering care planning

- Full achievement: practice demonstrates that 50% registered people with diabetes have a care plan
- Partial achievement: practice demonstrates that a 25% of people with diabetes have a care plan

Stream B:

Attend 'Preparing your practice for care planning': 1/2 day
Submit detailed action/ implementation plan for care planning in practice
Attends training when places available

- Full achievement: as above
- Partial achievement: attends preparation session only: satisfactory explanation of why not going forward
- Payment structure: one or two points for full or partial achievement of 11 elements of the LIS (care planning is one element – all related to diabetes or LTCs) ie maximum 22 points. Full for care planning = 26p per patient; partial = 13p per patient. Total possible for all elements £1.98 per registered patient on list

LIS for 2010/2011

Builds on 2009/10 (supported by use of YOC IT)

Mandatory

Attendance at training: all clinicians involved in diabetes not precisely trained

All registered patients to be involved in care planning within three months of training

Care planning to include:

- Invitation and explanation
- Information gathering visit for tests and screening
- Results by post to individual one week prior to care planning
- Structured care planning consultation
- Goals and actions available for individual to take away, and stored in the medical record

- Provide details of a subset of patient goals agreed during care planning consultations and reviewed within six months: for 25% of all people on register
- Full achievement means completing all parts

Optional element

To complete a self reflection tool (provided) for a total of three patients following care planning process

- Full achievement as above
- Partial achievement: attends preparation session only: satisfactory explanation of why not going forward
- Payment structure: one or two points for full or partial achievement of 11 elements of the LIS (care planning is one element – all related to diabetes or LTCs) ie maximum 22 points. Full for care planning = 26p per patient; partial = 13p per patient. Total possible for all elements £1.98 per registered patient on list

Feedback

Will be provided by PCT within six months via newsletters, GP electronic links and forums

Appendix 6: Workforce summary

Workforce issues and service planning for people with Long Term Conditions (LTCs)

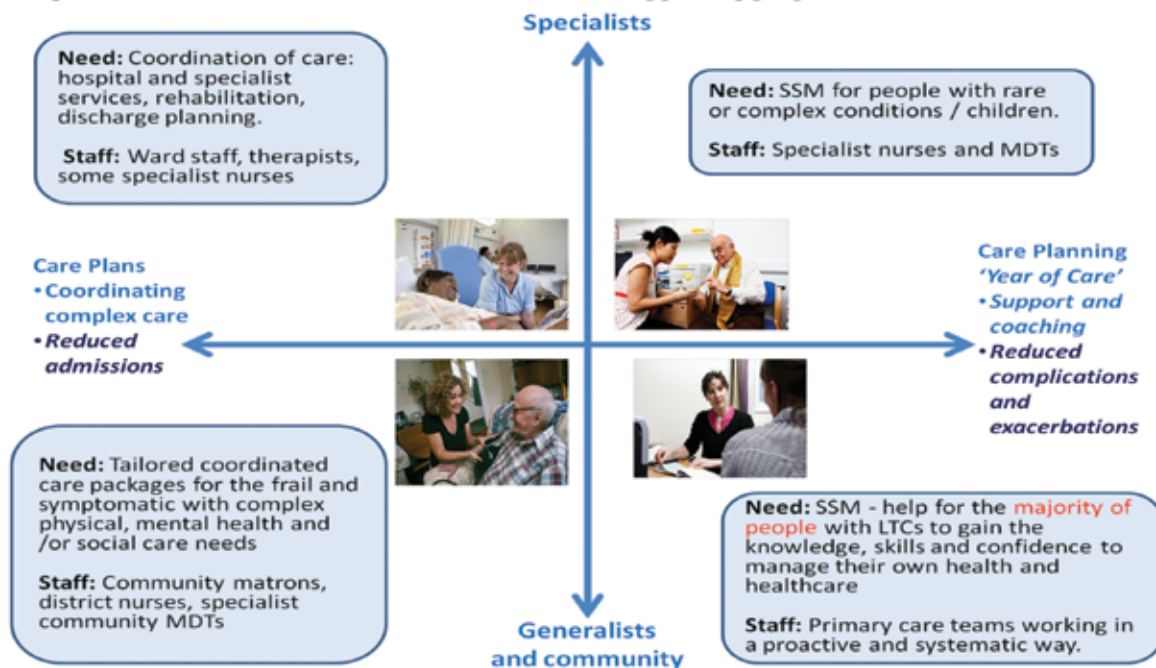


Questions: Which staff are involved in supporting people with Long Term Conditions (LTCs)?
Should services for people with LTCs be generic or disease/condition specific?
Should staff have generic or specialist skills?

Answer: 'It all depends!' There's no easy, right or wrong answer. People with LTCs are seen everywhere in the NHS because they have different needs at different times; staff working with them need a range of skills to match these needs. Some are generic and some condition-specific.

The Year of Care Programme observed: staff acquired skills quickly and confidently, if they understood their own role and where they fitted into the whole picture (Figure 1). Training was only effective if the context of care and the 'service infrastructure' were also understood and made fit for purpose.

Figure 1: Different individual needs and staff roles, supporting people with LTCs in the NHS.



'Collaborative care planning' is a way to support self management (SSM) and coordinate routine care for people with LTCs. Care planning may look very different in different settings.

Not all generalist care is generic! Generalists can have expertise in a group of conditions with similar issues (e.g. vascular, respiratory, neurological, musculoskeletal). Some generalists work with people to reduce symptoms, and gain immediate benefit; others need additional 'motivational' skills, if benefits are delayed but the required behaviour is unpleasant (more exercise, less food, more blood testing). As symptomatic physical, mental, and social co morbidity increases, generic issues of mood, mobility, isolation, bladder and bowel function overwhelm condition specific aspects. (Figure 1: bottom left quadrant.)

Everyone with a LTC needs 'Systematic care, 'SSM' and 'access to specialist care' when required.

Some people with complex needs also need **care coordination** (care plans)

Most people need **condition-specific understanding** to engage in their care, make decisions and choices and take medications appropriately. Compare using an inhaler, adjusting insulin, pain killers, and antihypertensives, with managing drugs for Parkinson's disease or epilepsy. Generalist staff need to know the key issues.

Commissioners need to design pathways and contracts that ensure people with LTCs see staff with the right skills in the right place, to ensure high quality and best value care.

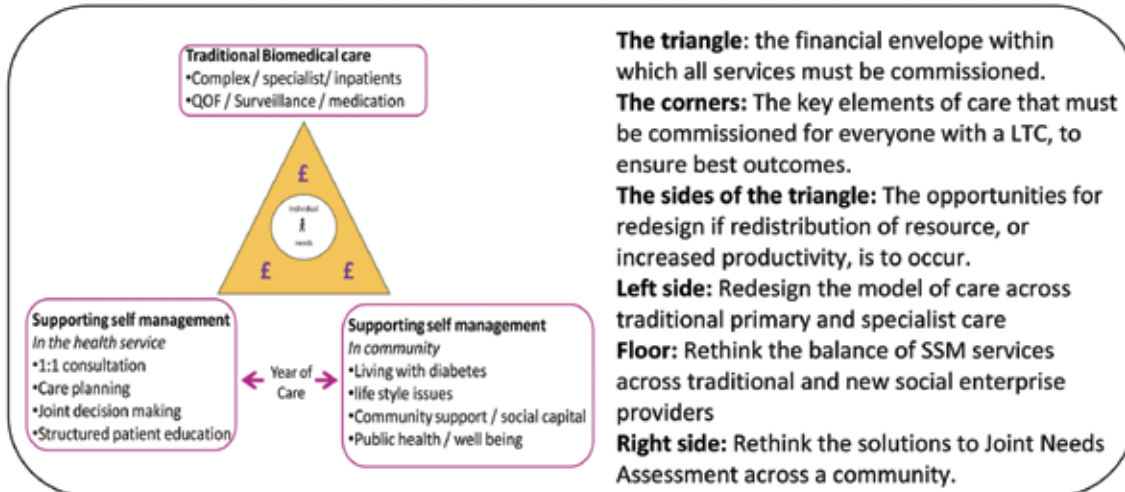
Appendix 7: Commissioning model for long term conditions (summary), Spring 2011

Commissioning model for long term conditions, Spring 2011



The Year of Care (YOC) Programme has articulated a new Commissioning Model for Long Term Conditions (LTCs).

Three diverse pilot sites (Calderdale and Kirklees, North of Tyne and Tower Hamlets), charged with delivering both personalised **care planning** in routine practice and new '**non – traditional**' services to support self management (SSM), were forced to rethink the principles and practice of service redesign across the whole local diabetes community. The model is an exemplar for other LTCs.



Grass roots commissioning: Using detailed understanding of local implications and costs, YOC sites were able to identify real and potential shifts in resources to support large scale improvement in productivity.

Examples: increased productivity across a range of local commissioning activities.

- 1. Unit costs:** Compare costs of traditional weight loss referral to a specialist dietitian (£21.25 per hour), with a tailored action plan developed with a qualified health trainer (£11.45 per hour) and linked to an individual's own goals identified at care planning (**Right side**)
- 2. Redesign of primary care 'packages':** NHS Tower Hamlets configured all practices into 8 '*Health and Wellbeing*' clusters linking Primary Care with Public Health, based on care planning for all (**Floor**)
- 3. Reduction in costs of improvement plans:** NHS Kirklees reframed the needs of people with LTCs after joining YOC. They redesigned their (QIPP based) patient centred improvement plan (**Left side**)

Business case for Diabetes service	2010 - 2011	2011 - 2012	2012 - 2013
Before Year of Care	265,889	185,898	0
After Year of Care	15,893	78,483	53,736

- 4. Reutilising a whole Programme Budget:** NHS North of Tyne identified £1.4 million across three localities for reinvestment in a patient centred model of care (**Left side**)

YOC provides a practical and effective way to implement locally driven flexible commissioning for people with LTCs and address '*no decision about me without me*' (*Equity and Excellence: Liberating the NHS*).

'It's 100% better for me and the patients' A GP

'This is the first time I have understood services in transition' Acute Trust Board Member

YOC has been recognised to support the QIPP agenda for personalised care planning
<http://www.library.nhs.uk/qipp/SearchResults.aspx?catID=15069&pageIndex=1&>

A partnership programme being delivered by the Department of Health, Diabetes UK, The Health Foundation and NHS Diabetes

Appendix 8: Year of Care Programme supporting documents and products

The Year of Care (YOC) Programme supporting documents and products

Getting to Grips with Year of Care: A Practical Guide: 2008

This document was produced at the end of the Year 1. It summarises the background and learning from the first phase of Year of Care (YOC) programme including the key thinking around care planning and commissioning. It introduces and provides an overview of the Care Planning House. It remains a useful introduction to the programme.

Partners in Care: A Guide to Implementing a Care Planning Approach to Diabetes Care: 2nd ed. 2010

This is the key guide to the philosophy and delivery of the care planning consultation and is an important resource for practitioners wishing to reflect on their practice and introduce care planning. It is used in Year of Care training.

Care planning – Improving the Lives of People with LTCs; Encouraging Partnership; Increasing the Quality of Care: 2011: RCGP

Produced here with kind permission of the Royal College of General Practitioners this document was produced with the support of key members of the YOC programme. It is a comprehensive account of the rationale for support for self management in LTCs, the case for change, and practical delivery and monitoring of care planning. It provides practical examples and key tips on how to introduce care planning at practice level by 'walking around the house'. It acts as a detailed 'how to do it' manual.

Year of Care programme report and Case Studies: 2011

This is the formal report on the Programme describing the background, aims and objectives, parallel evaluations, the way the programme was delivered and its impact. Case studies of each of the pilot sites are provided as companion documents. Together they include key learning about implementing the Year of Care approach to care planning and the lessons for commissioning for LTCs. They will be of interest to policy makers, those with broad interests in commissioning and service delivery of personalised care for those with LTCs, and anyone contemplating introducing and embedding a programme of cultural change across the NHS.

Thanks for the Petunias – A Guide to Developing and Commissioning Non-Traditional Community Services to Support Self Management of People with Long Term Conditions: 2011

This guide was produced in response to the discovery that there are numerous barriers and lack of experience in commissioning non-traditional community services to support self management. It outlines these issues and provides a commissioning and delivery model which addresses them. It will be of particular interest to clinical commissioning groups, public health commissioners and Health and Wellbeing Boards.

Theory and the Real World – What happens in Practice: Introducing a Complex Intervention Into a Complex Environment: Ten Challenges and Dilemmas from the YOC Programme.

Mind Your Language: The Year of Care Consultation Skills and Philosophy Toolkit

Range of one page summaries: key information/learning about the YOC Programme including:

- **The Year of Care Programme. Working Together for Better Healthcare and Better Self Care.** A two page overview including achievements of the programme, benefits and lessons for wider implementation.
- **The Year of Care Programme: Commissioning for Diabetes and other Long Term Conditions: 2011.** This single sheet outlines the YOC LTC Commissioning model with examples of increased productivity.
- **Workforce Issues and Service Planning for People with Long Term Conditions (LTCs): 2011.** This single sheet clarifies the differing needs of people with LTCs and the differing roles of NHS staff that provide care and support.

A National Training and Support Programme

This highly evaluated programme supports care planning delivery in primary and specialist care; this includes a quality assured 'training the trainers' programme, tailored resources, support to facilitate delivery, and links with unique IT templates to record patient goals, action plans and need for support services.

www.diabetes.nhs.uk/year_of_care



www.diabetes.nhs.uk/year_of_care

