The Year of Care Partnership Programme

Working together for better healthcare and better self care

The Gold Standard approach to introducing and embedding care and support planning for people who live with long term conditions, multimorbidity and frailty.

As extended case Study

Document 1: The Year of Care Programme: key facts, development, core components and implementation issues; training and support, building the house and examples for those living with single conditions (or related conditions)

Document 2: The Holmside Story: How a single practice redesigned their entire service for people with single or multiple unrelated conditions using the Year of Care principles

Document 3: How the Year of Care principles and practice can be transferred to other situations focusing on those with multi morbidity and living with frailty.

The Year of Care Programme works at the 'grass roots' to provide practical and effective support for local communities including;

- ***What*** needs to be in place to enable care and support planning to become normal care for people who live with Long term conditions

- ***How*** to do it with tailored support

The Year of Care Programme – key information

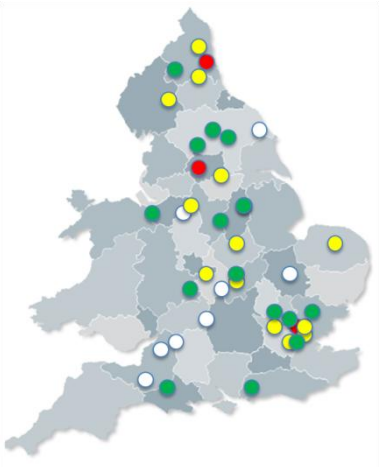
Personalised care and support planning is a central demand of people who live with long term conditions (LTCs) and a key component of current policy initiatives to provide them with person centred coordinated care.

The Year of Care programme (YOCP) has demonstrated how to introduce and embed this into routine practice for all those living with LTCs, multimorbidity and frailty and how to transfer the core principles effectively to enable teams and health communities to get started in working in this new way.

Based in three primary care communities, and using diabetes as an exemplar the YOCP developed a systematic approach to care and support planning and identified what needs to be in place in local teams and communities to achieve this. Using a process of structured development, support and training the core components have now been successfully transferred to;

- Other single or related groups of conditions; those with multiple unrelated conditions within a primary care setting; the elderly and those living with multimorbidity and frailty.
- Other settings ; specialist health, community, MDTs, *and*
- Maps across to other areas; e.g. personal health budgets and last years of life.

The Programme has worked with 30 local communities (e.g. CCGs, provider groups, whole health communities), more than 15 individual practices, 14 personal health budget sites and a large national charity to use care and support planning as a way to initiate system wide change. Over 4000 practitioners have received 'cascade training' from more than 60 quality assured trained trainers. YOCP is increasingly recognized as the 'gold standard' to support Specialist Clinical Networks , CSUs and



other bodies as they design their local engagement and delivery programmes. Based on a core set of principles and a rigorously developed curriculum modified to the needs of each community, Year of Care provides a practical programme to enable new communities to get started and redesign their services for people living with LTCs, with economies of scale. The programme is developing a learning network, for support and shared learning and developing clinical champions and exemplar practices.

Impact - Communities working with the YOC approach have been able to show

- Improved 'patient' experience
- Positive changes in self- care behaviour
- Improved knowledge, motivation and job satisfaction for staff
- Improved team work , practice processes and organisation
- Improved clinical indicators across populations after two to three care planning cycles
- Cost neutrality at practice level and savings for some
- Suitability for diverse communities thus reducing inequalities

Before things used to get forced on you…whereas this way I prefer to discuss it … Person with diabetes

If I were a patient I would want to have a care planning system in place. I think it respects people more as individuals. PN

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

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 LTC

It's 100% better for me and the patients. GP

I'm listened to – you may not have all the answers but you've helped me work it out. Person with LTCs

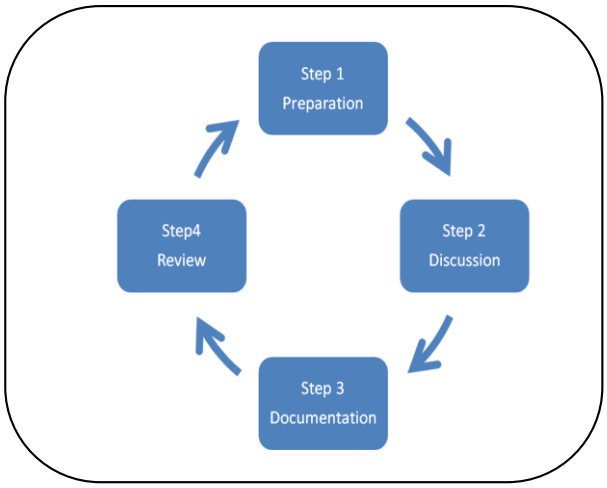
Care and support planning - The Year of Care approach

Care and support planning is a systematic way of ensuring that individuals living with one or more long-term condition (LTC) and their health and care professionals have more productive conversations, focused on what matters most to that person. It is a 'meeting of experts' bringing together those with technical expertise and those with lived experience to identify issues, establish priorities, develop solutions and initiate actions both for the individual and for the service. Care and support planning should be integrated into core care packages and pathways designed to bring physical and mental health together within in a social context.

Care and support planning links traditional clinical care and support for self management for each person, signposting to activities within a supportive community *('More than Medicine')* and coordinating with social care (and other services) where relevant. The result is a unique, personalized response for each of the 15 million people living with LTCs in England.

The key parts of this conversation are recorded in the care and support plan which brings all health and care issues and actions into a single place, however many conditions the person may have. But it is not an end in itself. The important part is the conversation that precedes it.

Care and support planning is a continuous process of planning and review and is not a one off event. It replaces the often disjointed contacts people with LTCs currently have with health and care professionals.



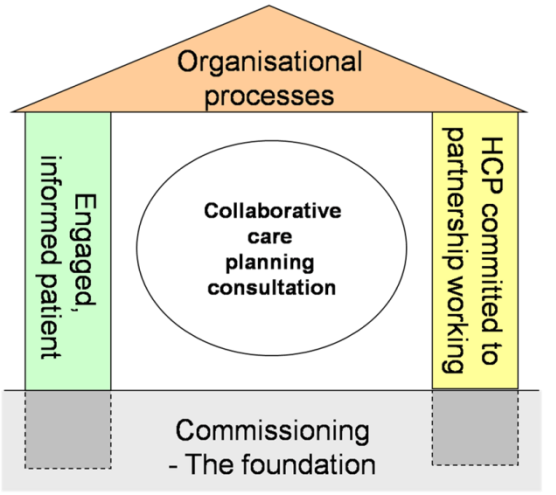
National Voices have recently taken the learning from YOCP, to describe care and support planning as

a four step process set within a clear philosophy of practice. The YOCP has adopted their language to support clarity and consistency.

Details of the philosophy and steps and how these can be adapted to design services for any group of people living with LTCs are important components of the YOCP core training and support programme. **Document 3** in this series provides a worked example for those living with multimorbidity and frailty.

The House of Care

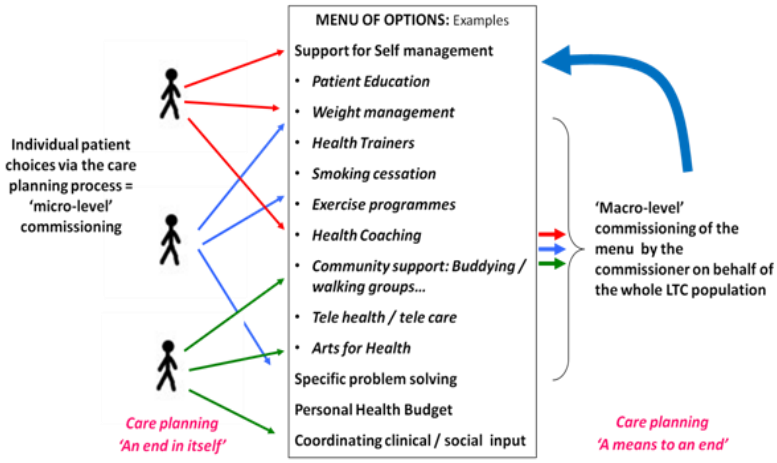
Year of Care pilot sites realised that these four steps could not take place within the confines of the current ways of working. The issues that needed to be addressed fell into four groups which became the walls, roof and foundations of the 'House of Care'. This demonstrates that effective care and support planning consultations rely on four elements working together in the local healthcare system: an engaged, empowered person working with Health Care Professionals (HCPs) committed to a partnership approach (the walls), supported by appropriate/robust organisational systems (the roof) and underpinned by responsive whole system commissioning.



The House Model acts as a check list of what needs to be in place, and also a metaphor for the interdependence of each part, if one is weak or missing the structure is not fit for purpose. It also provides a flexible framework around which communities can design the sort of house to suit their population.

Linking care and support planning with *'More than medicine'*

The YOCP programme recognised that that people with LTCs spend a very small proportion of their life with health and care professionals. It acknowledges that people living with LTCs manage their conditions and challenges posed by treatments and symptoms every day, and benefit from the support and resilience that peers and local communities can provide.



Care and support planning includes the opportunity to signpost individuals to *'More than medicine'* activities that match their goals, aspirations and plans. These recognise the social as well as the medical aspects of long term conditions, and are often deeply embedded in the communities they serve and can provide more 'tailor made solutions'. For some people with LTC's, health trainers, volunteers and peer supporters can facilitate and cement these links. Engaging with 'non-traditional providers' is an effective means to better social and clinical outcomes for people with LTCs, more cost effective use of NHS and social care resources and widening of the local provider base. This aspect is an important part of the foundation of the House of Care.

The YOCP has produced a publication which outlines the issues involved in providing and commissioning a comprehensive range of *more than medicine* services and link workers.
http://www.yearofcare.co.uk/sites/default/files/images/nks%20for%20the%20Petunias%20%20a%20guide%20to%20developing%20and%20commissioning%20nontraditional%20providers%20to%20support%20the%20self%20management%20of%20people%20with%20long%20term%20conditions.pdf
Further information is available from the People Powered Health project:
http://www.nesta.org.uk/sites/default/files/more_than_medicine.pdf

Building the House of Care

The Year of Care programme has extensive experience both about how to introduce and embed care and support planning using the House of Care and also how to support local communities to do this.

The House of Care describes ***what*** needs to be in place for people living with LTCs to deliver person centred coordinated care but it is up to each local community to decide ***how, when, where*** and ***by whom*** this is best provided for their local population. These details form the local 'model of care' and the foundation for local commissioning.

Building the local house of care is best achieved in three stages which all require active local leadership, accountability and management throughout.

Stage 1: Setup and preparation: This ensures that the right people are seen at the right time and in the right place as part of a system wide approach. It starts by identifying the group for initial focus (e.g. single disease, multimorbidity) and then designs the local pathways and packages making up the model of care for that group, ensuring that care and support planning is central to these. Setting up a Steering Group to oversee the introduction, work with teams to fill gaps, overcome barriers and use metrics for learning and long term improvement is a critical component. Clear intentions of the purpose of implementing care and support planning should be articulated as part of the local LTC strategy with baseline measurement used to assess ongoing impact. Using the components of the House of Care as a structure for meeting agendas and activities can be helpful.

Stage 2: Implementation: This stage is about introducing and embedding care and support planning, and 'more than medicine' services into local practice using the House of Care framework. This includes engaging care professionals and ensuring that high quality

training designed to achieve culture as well as system change is available for delivery teams, and that the various components of the house are in place.

Stage 3: Ongoing maintenance and sustainability: Maintaining new habits and ways of working is hard. The Steering group needs to ensure that care and support planning is actually happening and that there is ongoing support for teams, further skills training as need is identified, metrics are reviewed and fed back and opportunities are provided for the practitioner to reflect and develop with peers.

Key criteria for success: summarised experience from the YOC programme

- Culture ***and*** systems must change to support a new way of working.
- When considering successful delivery – it's not only what you do, it's how you do it.
- 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.'*
- Delivery is context specific and staff must be clear about their roles, and where care and support planning fits into the local pathway / model of care.
- There are extra costs at start up for communities with poor health literacy.
- Care planning is about cultural change and this takes time – staying in for the long haul delivers.

Year of care training and support programme

Right from the start it became clear that high quality training was crucial to success; but training could not be viewed in isolation from the changes in the organisation and infrastructure needed to support its introduction.

The YOCP team offers an approach that includes working with a local community during the set up phase, and then providing tailored training in attitudes, skills and organisational change at team level for practitioners who will be involved in delivering care and support planning as part of their routine jobs. This includes 'awareness raising' events to introduce and engage grass roots teams with the core values and concepts of care and support planning, including a compelling case for change, prior to attending a core training module.

The training is then delivered over one day and then a half day six weeks later, to enable participants to begin the process of change within their teams and compare experience with colleagues. The core programme includes all the resources that would be needed to get started, including practice packs for practice managers, and further training modules for health care assistants. Training specifically tailored for community and personal health budget teams has been developed and a module on advanced consultation skills for practice nurses is also available.

Where communities want to sustain the approach and develop local capacity both a quality assured training the trainers programme, and modules for practice facilitators have been developed. These are designed to maintain the integrity of the YOCP approach and reassure both people living with LTCs and commissioners that training is of high quality and consistent with the approach which has been linked with positive impacts.

A clear and comprehensive set of guidance for local organisers to support preparation for training, identify local trainers and help sites identify clinical champions is also available.

'Making it easier to do the right thing'

Core training for care and support planning weaves together activities which challenge mindsets, provide opportunities to observe and practice consultation skills as well as time to start thinking about the organisational change that will be required by each team to enable

this new way of working to happen. The learning environment is designed to enable teams to work together and start the process of shared learning. Teaching includes discussion and clarifications, modelling and observation of care planning, practicing new skills and developing participants own goals and action plans to implement in practice. Themes covered include the underlying philosophy, organisational aspects of 'building the house', care and support planning consultation skills and using a goal setting action planning approach.

> ***'It's made me reconsider my consultation skills and I will definitely change my practice to make it more patient-centre'***
>
> ***'You have converted a cynic'***

Training the Trainers is a quality assured developmental programme designed to build local capacity.

It involves taking part in the one and a half day core training and then attending a three day train the trainer's event to get greater insight into the underlying educational principles and delivery of the programme, to have opportunities to practice in a safe environment and to explore how to maximise local opportunities and handle challenges. Trainees then co deliver the programme with an experienced peer trainer and finally are observed delivering the programme and given supportive feedback.

Guidance on success factors and criteria for trainers is available. Following training, trainers have access to training materials, shared resources, updates and the developing network.

The Year of Care programme – background information and evidence base

Launched by the Department of Health in 2006 The YOCP was hosted and co sponsored by Diabetes UK. Parallel evaluations provided greater understanding of implementation issues and these were summarized in the Final Report. Lessons from spin off projects and parallel work elsewhere in the country were incorporated.

The core team members and the accumulated learning, expertise and resources are now based within Northumbria HCFT, so this can be made available to others in a partnership approach enabling spread and further development for other LTCs. The Year of Care Partnerships team has now worked with many NHS and third sector organisations to provide tailoured training and support synthesising local learning into increasingly robust models of care and support planning covering the entire range of LTCs.

The YOC approach was developed from a robust international evidence base which both describes the principles of healthcare delivery for people with LTCs using the Chronic Care Model and also what works at the level of individual encounters to support self management, behaviour change and increase knowledge, skills and confidence. The training and support programme is based on principles of adult learning, skills development and attitudinal change; the training the trainers programme uses quality assurance approaches derived from the best teacher development programmes; and the approach to facilitation is also evidence based.

Examples

The following examples illustrate different dimensions of the Year of Care programme for single conditions, or related conditions. They variously demonstrate that care and support planning greatly improves care experience and engagement in health, but is also associated with improved care processes, and clinical outcomes and staff job satisfaction. Features that have been important include local leadership via an active steering group, especially when it involved service users in coproduction (Tower Hamlets and Bexley), data collection and feed back to teams in useful ways (Tower Hamlets, Cumbria), practice support and mentorship (Bexley) and long term consistent primary care leadership from those who are developing care and support planning in their own practice (Cumbria). The North Tyneside approach to COPD illustrates that care and support planning is as suitable in a person's home as in practice clinics, and Nottingham has shown effective care planning in specialist centres improves experience and attendance and can be the site for local leadership.

Companion documents **(Documents 2 and 3)** describes how care and support planning can be provided for everyone with any number of co morbidities within general practice **(the Holmside story)** with economies of scale and improved working practice and job satisfaction for staff; and also describes the details of the philosophy and steps of care and support planning and how it can be adapted for those with the **most complex health needs** (those living with ageing, multimorbidity and frailty.

Tower Hamlets: Care and support planning as normal care for people with Type 2 diabetes and its positive impact on the National Diabetes Audit items.

Tower Hamlets, an area of high deprivation and ethnic diversity, was one of three YOC pilot sites with a central role in developing principles and practice using the House of Care approach. This was led by an active Steering group including the local PPI lead and people with lived experience of LTCs ensuring that their robust local links across the community were central to the programme. The group worked with the whole health community including specialist care and used metrics and multiple data sources to monitor progress and feedback to practices. The positive experience of the 8 initial practices led to the approach being rapidly adopted by the local primary care networks which were then being developed. A similar approach was introduced for cardiovascular conditions and more recently for those with complex psychosocial conditions and high users of NHS services.

In 2005 Tower Hamlets had indices for Type 2 diabetes care amongst the worst 10% of PCTs in England. By March 2012 it was able to report the best. Care and support planning is now the norm. Data (no exclusions) is available for all people with diabetes up to March 2012. 95% have had at least one annual care planning consultation and 40% more than one. Because the measures which are at the heart of good secondary prevention are routinely collected and shared with each individual as part of the care and support planning process measurement has improved dramatically. Ninety six per cent of people with Type 2 diabetes have had the three 'traditional' components of diabetes care (HbA1c, BP and

cholesterol) measured and 74.2 % have had all 9 components within the National Diabetes Audit recorded. This value is the highest reported in England: (Average 54.3%).

Biomedical outcomes have also improved; the proportion of people with good control of all three indicators for developing diabetes complications (HbA1c, blood pressure and cholesterol) have increased from 24% to 35% (England average 20%). Tower Hamlets has also been able to show that QOF indicators for cardio vascular conditions improved more than similar neighbouring CCGs and the incidence of acute cardiac conditions fell faster. Because of the other organisational changes occurring simultaneously, it is not possible to prove direct causality between these important improvements and the YOC approach. However the improvements in patient experience, job satisfaction, and organisation to support self management within practices were directly observed. Positive answers to the question in Picker surveys in Tower Hamlets 'I *have had about the right amount of involvement in my care'* rose from 52% in 2006 to 82% in 2009. This illustrates that providing improved care for people with diabetes and other LTCs is not a separate challenge from that of providing tailored support for self management to each individual. They are part and parcel of the same approach, because personalisation of care itself can stimulate better traditional clinical care with economies of scale for practices, teams and training.

Stakeholder views from Tower Hamlets

- *'YOC is a great idea because it is focussed around the individual. I'm happy that I get more of a say in my care.' (*Person with diabetes from Bengali community - TH submission*)*
- 'It *has given a more structured, planned approach to diabetes. ….. We now see them in a structured way and call them back – to patients it looks like we know what we are doing.'* (GP1)
- *'Care planning has made me look at patients differently. I focus less on the disease and take a more holistic perspective. … if someone has arthritis there is no point referring them for more exercise.* (Nurse7)
- *'While a lot of the improvement is related to …. reorganisation in primary care there is no doubt that YOC has dramatically improved how patients relate to their diabetes. I rarely get a referral from someone who hasn't a clue …the penny has dropped for a lot of people.' (Specialist diabetologist)*

Bexley: A planned approach to achieving and sustaining culture and systems change.

Bexley PCT was the first Year of Care community to introduce care and support planning beyond the pilot sites and provided much of the learning for the YOC training and support team about how to transfer and improve the programme, in a way that enables a local service to build on the core components, tackle issues and then make this new learning available for others.

Bexley PCT were able to use the drive and enthusiasm of the local Diabetes UK group which provided an active lay Chair of the local Steering Group together with the enthusiasm and passion of the project manager who himself lived with diabetes. Using the experience of the YOC pilots they engaged both key members of the managed clinical network as well as the CEO of the PCT to provide local leadership in setting up an enhanced service for GPs in which care and support planning was a key component. This brought on board clinicians who initially were not enthused by the programme and had confused notions of what care and support planning might be and its relevance to diabetes care. Following the first round of YOC core training a local GP lead was identified to become a champion among her peers and she went on to become a trainer and a key member of the implementation group, which also included someone with lived experience as part of the design team. The Steering Group worked to provide a varied training programme for primary care including many aspect of diabetes, and actively worked with GP practices following training to ensure that those involved in care and support planning were well informed and confident. They learnt that this work needed someone with protected time as well as administrative assistance. It was vital for the project manager to have attended care and support planning core training so she could be of practical support both to practices, and well informed in terms of engaging the public. They identified the need to work with people living with diabetes early in the new programme, and addressed practice issues including IT in practical ways.

The Bexley team identified the need to record outcomes as well as process data and feed it back to primary care. They put together a Diabetes Practice Development Team (DPDT)

comprising a GP, a diabetes specialist nurse and a patient representative. The team's role was to visit Bexley's 28 GP practices following an annual diabetes audit and patient survey. The aim was to identify barriers, help practice development and sustain motivation. Where they identified a need for more specific support a formal mentorship programme was initiated which enabled an experience trainer to work with individuals one to one.

Selected impact of the Bexley diabetes programme

'The patient's voice is central and is directly involved in design and delivery'

- 97% of practices developed accurate registers , 100% taking part in national Audit
- 93% of people living with Type 2 diabetes were involved in care and support planning
- 96% of practices trained in care and support planning
- 20 fold increase in attendance at structured education (X-PERT) : 50% lay trainers: Positive 'patient' feed back to practices increased referrals
- Increased 'patient' satisfaction in, and confidence to undertake diabetes management
- Increased patient confidence in receiving care in primary care (91%)

'I used to attend the local hospital but find it much easier to attend the diabetes clinic at Lakeside Medical Centre' **– person with diabetes**

- Best glucose control in London: 60% achieved HbA1c < 7% (London average 52%):
- National Programme Budget: best low cost / good outcomes in England
- Referrals to secondary care halved

- Member ship of local Diabetes UK Group doubled

Nottingham Specialist diabetes service:

The specialist diabetes team in Nottingham had a long standing interest in support for self management and the Year of Care philosophy, and were keen to see if care and support planning would work in specialist settings. Following core Year of Care 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 and support planning

appointment. They developed a short training course for the clinic healthcare assistants (HCA) and this ensured the whole team understood the philosophy.

The specialist team have always had a close working arrangement with primary care and made training including HCA training available to local practices. The HCA sometimes became the driving force behind change, encouraging their GP and practice nurse to come on the training.

By the end of June 2011, about 50 doctors and nurses from primary and secondary care had trained together and trainers had been identified to help local spread. They continue to run courses and provide an annual update. The CCG has asked that other consultants begin to start working in this way, and interest is coming from other local CCGs.

The team also adopted this way of working in Insulin pump clinics and has recently (January 2014) set up a new integrated diabetes service in various sites across Nottingham for people with Type 1 diabetes as well complex Type 2. It is based on care and support planning with the aim of engaging people who have not found the previous service helpful. In the general diabetes clinics in the hospital the non-attender rate has now fallen as low as 5% which is amongst the lowest in the hospital.

Nottingham Specialist Service

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 more"*

Staff has 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'*
- *'do you know what TEAM means? Together everyone achieves more – and we are working as a team'*

Cumbria specialist and community service: active ongoing support across a large geographical area

Cumbria has been systematically developing care and support planning in primary and specialist care for diabetes since 2010 and is now proposing to start introducing this for those with complex needs. There are 93 practices over a large dispersed area with complex communication links round the landmass of the Lake District, There are pockets of affluence and significant areas of post industrial deprivation mainly along the coastal strip. Despite this a small group with GP leadership has been able to systematically increase the interest and uptake in YOC which is now spreading by word of mouth.

Cumbria has the highest uptake of DESMOND in England (a structured education programme for Type 2 diabetes in England) and this led primary care teams to recognize the benefits of involving people in their care and the value of central coordination. In 2011 the central team offered YOC care planning training to practices across Cumbria as part of a local enhanced service and trained 5 local trainers. Awareness raising included local media, a user group, practice support, IT, practice visits and networking to support implementation. The diabetes specialist service who was also trained (1 consultant, 1 specialist dietitian, 4 specialist nurses) actively promoted and introduced the approach as routine in their clinics.

Initially the team struggled to know what was going on and how to quality assure across such a large dispersed group of practices. But an annual structured questionnaire, showed a gradual increase in uptake from about 50% in the first year, identified a group of early adopters, and enthusiasts as well as highlighting the challenges and barriers. The importance of IT was addressed by strong links with the PRIMIS facilitator who joined the planning group and this led to the development of national codes for care planning as well as a dataset to be included in the local diabetes dashboard which included a measure of patient enablement and care quality 'Living with Your Diabetes'. Other philosophical and

organisational issues were discussed collectively at locality meetings supported by local champions and the national YOC team. By April 2013 approximately 80% of all GP practices had attended YOC care planning training and the majority of these reported implementing changes in their practice to support patient preparation and a care planning approach. Since April 2013, practices have been incentivised to apply care and support planning principles to people with conditions other than diabetes, including taking an holistic approach to support people with complex care needs and co-morbidities. This is ongoing work, beyond the boundaries of traditional general practice, and is beginning to inform and describe the shape of an emerging and more functional health and social care community, with support for people with long term conditions at its centre.

Cumbria – community and specialist services

People with Diabetes have said: This has made managing my diabetes much easier as I can see how it is progressing. I feel supported by my practice – my experience so far has been very positive.

The Specialist team said : We feel it is important for primary and specialist care teams to be using her same language and approach via care planning to ensure seamless care and a holistic joined up approach.

General Practitioners have said: People have put more thought into their care and taken responsibility for their own treatment and the care they receive. Care planning for diabetes has gone very well. It should be expanded to include other long term conditions.