

Patients as partners in developing Self-management solutions: Co-design Case Study

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Carer Support – NHS Mid Essex
CCG

Co-design Case Study: Carer Support in Mid Essex CCG

Mid Essex CCG took part as an early adopter in the Patients in Control PiC Programme in 2014/15. This case study describes the journey as an early adopter and highlights important learning.

An interest in self-management

Mid Essex CCG sits in the East of England covering an area of 522 square miles with a mixture of urban and rural populations. Its population is relatively affluent with above average health outcomes but like many CCGs it is facing considerable financial pressure on its budget of just under £400M.

The CCG cares for 100,000 people with Long Term Conditions (LTCs) of which 12,000 have multiple LTCs. It has published a five year transformation plan The Way Ahead where LTCs is one of seven linked transformation plans and increasing self-management an integral part of the plan.

The involvement in the Patients in Control (PiC) programme as an early adopter was supported by the CCG governing body and commissioning leads identified carers as a local priority. Its aim was to develop more carer support across the CCG area in the hope that more consistent provision will help unlock funding for carer support in the context of the Care Act coming into effect on 1st April 2015.

*“Patients and carers are often the people who know best. They are able to design solutions from a grounded approach.”
which can produce much better results.”*

Jane Hanvey, Mid Essex CCG

Gathering insight and building local understanding

The CCG identified Action for Family Carers (AfFC) as a key voluntary sector partner in recruiting and supporting participants. Action for Family Carers was already in touch with a large number of local carers and its support was highly valued by carers.

AfFC undertook a direct mailshot to all carers inviting and promoting their involvement in the work. It organised the venue and refreshments for the first session but was unable to attend because of competing pressures and demands from providing front line support to carers.

“The co-design sessions were an opportunity to come together: the professionals, the carers and the cared-for; and for each to share their point of view...”

Leanne Dovey, AfFC

The first two insight gathering sessions took place in September and October 2014 and involved between 10 -17 participants of mixed gender, over 50's who are caring for and/or living with a long term condition. Many were the main carer for loved ones who were living

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with dementia.

The third co-design session took place in January 2015 involving the core of participants, the CCG Interim Transformation Programme Director and Action for Family Carers. The focus was to identify how the carer's needs for support might be met going forward.

What mattered to carers

There was consistency and passion in the challenges identified:

- They often felt excluded from the care decision making and 'conversation' between doctors and patient and their experience of communication between different professionals and care agencies was often very poor
- They often struggled to find good, reliable information about the condition and prognosis for the person they care for
- At a very practical level, they found it difficult to find out about sources of financial help and support and sometimes felt there was a lack of transparency about what support was available
- They found it difficult to access affordable and reliable respite care especially short term and often neglected their own health care needs as a result
- They felt frustrated at the perceived lack of status of carer in the eyes of health professionals and felt they were not listened to and often unsupported in meeting some care needs for which they had neither skill or experience
- They felt there was variability of General Practice in the extent to which they cared for carers – a good GP making all the difference helping signpost to available services and support.

"Carers don't believe that the NHS, social services or charities are talking together in the way that they should."

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Patients and carers as partners in innovative commissioning

The co-design stage with a wider membership focused on the following areas of support identified as priorities:

- **A "one-stop shop" for advice and information** – they did not want to waste scarce time and energy trying to navigate fragmented sources of information about financial allowances, support and grants that may be available to them. AfFC was highly valued by carers as source of advice and support but there was real concern that some carers may not access available support because of perceived weakness in communicating information and providing practical support in sourcing information on the internet.

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- **Better care for the carers** - they felt under a lot of emotional and physical stress and this had a detrimental impact on their health and wellbeing that could threaten the sustainability of the partnership between carer and cared for. Some local provision in General Practice was good at proactively identifying and meeting the needs of carers but there was considerable variation and inconsistent support in some Practice settings. Adoption of the Good Practice Guide which has been developed between the Royal College of General Practitioners and the Carers Trust would help secure things like faster appointments for carers, flu vaccination, better signposting to sources of support

“Carers share the same concerns - we’re all under stress and we neglect our own health. In my case that’s because I am so concerned with looking after my wife.”

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Value of approach and benefits

For the commissioner

Understanding – provided a deeper level of understanding about what works or doesn’t work that was directly informed by experiences of carers.

Defining priorities and shaping solutions: the involvement of carers in identifying the practical challenges and priorities and co-designing practical solutions meant there was greater confidence and assurance that solutions would be realistic, relevant and properly targeted to meet the needs identified as priorities.

Maximising impact and benefit – learning about what really matters to carers and having the readily usable evidence to back it up could be used to start to impact on all pathway redesign within the CCG so that benefits are maximised.

Reinforcing the cultural shift in commissioning - the co-design approach provided the evidence and tools to bring the needs of carers into broader CCG discussions internally and externally with partners with the report helping to make a compelling case for action.

“We still have a lot of work to do around the pathway redesign but we have already started to involve carers into some of our long-term conditions work.”

Jane Hanvey, Mid Essex CCG

For the voluntary organisation

AfFC felt that taking part in the co-design sessions had been valuable in highlighting the considerable challenges faced by carers and the importance of getting some of the basic support provisions right.

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“It was an opportunity for carers to speak openly and honestly to people who wanted to listen.”

Leanne Dovey, AFFC

to valued and listened to. It was important that they had been able to discuss issues that matter to them face to face with a senior commissioner from the CCG who was listening to them rather than ‘talking at them’.

For carers

Carers valued the co-design approach because they felt:

- Listened to and able to influence commissioning priorities and decision making
- Regarded as equal partners with valued ideas and input to make to commissioning
- Acknowledged that carers know best about the needs of carers
- Empowered through sharing experiences with other carers that helped put those experiences into perspective.

“To actually get someone there from the CCG – a real person, making real decisions – saying ‘we’re going to do that’ and ‘we can do that quite easily from now on’.”

Leanne Dovey, AFFC

As positive as the carers were about the experience of being involved in the programme, they were very aware that this was the start of an important journey that will only be validated and proved worthwhile once the support available to carers starts to improve. They appreciated this will take time but were looking forward to seeing evidence of impact.

There was also concern that annual contracting cycle for voluntary organisations not only diverted energy and resource but sometimes resulted in major upheaval and dilution of the support available to carers and loss of experience, knowledge and skill from the care support market. Most carers were able to look back to a time 3-5 years earlier when they felt better supported in looking after their loved ones.

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Learning and reflections

- Allow time for the group to discuss and shape the issues – it is key to understand these fully before moving to co-designing solutions
- Be prepared for some scepticism among participants if discussion groups have been held before without leading to action. Demonstrate to participants that the co-design sessions are going to lead to tangible outcomes, and make sure they do otherwise the outcome of the sessions could be negative.
- Think about how to cascade / share information from the co-design sessions within the wider CCG and partners so that it becomes embedded in the organisation and wider partnership working
- The strength of the economic case for commissioning better support for carers is compelling. Helping carers stay healthy and well so that they can continue caring for their loved ones is not only better for the carer and cared for but also a sound commissioning investment.

“The only closure for participants will be if something changes. Otherwise for them it’s just another talking session where they have been giving their views then been ignored.”

Jane Hanvey, Mid Essex CCG

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