

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

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Diabetes Care – Crawley CCG/  
Horsham and Mid Sussex CCG

## Co-design Case Study: Diabetes care – Crawley CCG/Horsham and Mid Sussex CCG

NHS Crawley Clinical Commissioning Group (CCG) and NHS Horsham and Mid Sussex CCG had been working jointly on a person-centred care initiative, a core component of their House of Care model, when they accepted an offer from the Patients in Control (PiC) Team at South East Commissioning Support Unit (SECSU) to facilitate co-design workshops. Although they had taken part in the online patient and carer insight survey, conducted in 2014 across the South, Midlands and East of England by SECSU<sup>1</sup>, only a small number of people from Crawley, Horsham and Mid-Sussex had responded. The two CCGs felt the patient insight would enrich and further advance their plans.

The initiative supports the CCGs' plans to empower people with long-term conditions and to support self-care through professional skills development. It also aligns with the NHS 'Five Year Forward View' for empowering service users and challenging the traditional divide between patients and professionals. To introduce this more inclusive approach to care planning, the CCGs were keen to bring patients and carers together with commissioners to explore how best to develop a more person-centred approach to care for people living with diabetes. They saw this as starting point for engaging with the wider population of people affected by diabetes.

The principles by which the CCGs aim to deliver this care are:

- **Standardising collaborative care planning** - Every diabetic patient across NHS Horsham and Mid Sussex CCG area and NHS Crawley CCG area will receive the same standard of high quality, personalised care that puts them as an individual, at the centre.
- **Personalisation** – Patients who can talk about their health, social care and holistic needs, (including psychological and wellbeing needs), as part of the care planning process will enable care professionals to understand what really matters to them and ensure their treatment/support is built around them as an individual.
- **Enablement** – Through consultative practice, care professionals will be able to deliver more effective support to patients to help them manage their long term condition more effectively, seeking the appropriate help in a timely fashion (and reducing reliance on statutory services), as well as empowering people to develop the knowledge, skills and confidence to self-manage.

### Benefits were seen to be:

- Increased activation, engagement
- Shared decision-making
- Personalisation and choice
- Better outcomes for service users

Feedback from the sessions would therefore provide valuable insight which could be used in training for healthcare professionals on consultation styles, care planning techniques, increasing service user participation in care planning and goal setting, and developing champions and leadership amongst practice staff.

<sup>1</sup> Previously known as Kent and Medway Commissioning Support Unit (KMCS)

### Gathering patient/carer insight

The PiC survey with patients and carers gave insight into how they managed their long term health condition. It emphasised that what matters to patients and carers is similar, irrespective of geography, demographics or condition.

The two CCGs had also sent out a local patient experience questionnaire to patients from three practices (one in each locality). Twenty four percent (124) out of 518 people responded. The results, which upheld the findings of the wider PiC survey results, indicated that:

- Most patients felt that they had received an adequate explanation of their long term condition and were aware of what to do if they were concerned about their condition or treatment
- Just over half of the respondents had been given information about local support groups and most patients were aware of the lifestyle changes required to improve their overall health outcomes. **However, less than two thirds felt able to make the changes necessary**
- **Only two thirds of respondents felt in control of** their long term condition and less felt that they have had adequate input into decisions about their healthcare.

*"I'm a person and should be treated as a whole, not in segments of multiple health conditions."*

*Tony, a patient with diabetes*

### Building local understanding

Drawing on the local patient survey, the CCGs wanted to delve further into the views of patients with diabetes and/or their carers, to find out more about how best to achieve person-centred care for them by:

- Establishing "what's important to me" – if that is what people want
- Understanding how the CCG could support people to develop the knowledge, skills and confidence to self-manage
- Promoting this approach to people living with diabetes and support them to have a "different conversation" with their healthcare professionals.

### Working with patients as partners in co-design

Participants were recruited via the CCG Health Network, GP surgeries and local diabetes groups. A notice was also placed in a number of local newspapers giving details of the workshop sessions, to capture those who do not regularly attend their GP surgery. There was also publicity via a radio interview, promoting the PiC events. All forms of promotion appeared to yield positive responses.

Two sets of workshop sessions were set up – one in Crawley town centre and the other in the more rural location of Haywards Heath - between patients, carers, commissioners and other NHS staff.

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Seven people attended the sessions in Haywards Heath – three carers and four patients. In Crawley, eleven people attended of whom one was a carer. Both Type 1 and 2 diabetes were represented. Some had co-morbidities, many had lived with their condition for years, others had been more recently diagnosed.

A clinical director from the relevant CCG attended all sessions, alongside commissioning managers. The meetings were facilitated by an independent facilitator working with the PiC Team.

In preparation for the event, commissioners had provided some background information to participants so that they understood the aims of the meetings and what was expected of them. At the beginning of the first session the clinical director gave a very brief overview of the CCG's current strategy with regards to long term conditions and the aspiration to change their approach to care provision to become more person-centred. It was important at that stage, however, not to present preconceived ideas or solutions of how the CCGs planned to do this. The essential purpose of the PiC sessions was **to understand the patients' and carers' perspective** – which might produce a different outcome to what was being planned.

### Managing my own health means -

- **doing what is necessary to keep safe and well with as little intervention as possible**

Although the two CCGs were taking a joint approach, there were some distinctions between the localities. Participants raised specific local issues, such as the isolation of many villages with poor public transport links, the importance of the GP surgery providing several health services in one place and the shortfall in specialist diabetic nurses. Despite the presence of a local diabetic support group, many patients were not aware of it and had not been signposted to any non-medical support by their GP. Many of those participating had not been offered a place on the DESMOND diabetes education course and had struggled in the early days following diagnosis.

The message which came across in the sessions was that patients understood that they had a responsibility for self-management but needed guidance on how to do so confidently. Healthcare professionals also had a responsibility for ensuring that patients were equipped with the facts and knew where to get help if needed.

*"We're in this together – we want you to be well and get the best life while living with the condition."*

*Laura, clinical director and GP*

Themes which emerged from the events were:

- Access to specialist services was important if needed – especially in the early stages after diagnosis, though this need not always be with a consultant

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- Consistent, reliable information about living with diabetes and the risks was needed at the right time – and in a variety of formats i.e. verbal, written leaflets, courses and online tutorials
- Some GPs and primary care staff could benefit from additional training regarding diabetes care as they don't appear to be offering the level of service they are contracted to provide
- Professional attitude to the condition was important in getting the right message across and to help people to come to the decision themselves that they need to take control of their condition. Some felt that they were being judged or stigmatised because they had become overweight
- Communication between primary and secondary care needs to be improved.
- Healthcare professionals should take a holistic approach to care – many diabetic patients also have other health conditions and personal circumstances which can impact on their ability to manage their diabetes well.
- There was a need for a cultural change in attitude for both clinicians and patients.
- Patients and doctor should work together in developing a personal care plan, setting goals and both understanding how the patient was going to set about achieving them. This was seen as a 'living' document, evolving over time as needs and circumstances change. It should be shared with other professionals where relevant.

*“There is a stigma attached to diabetes, especially Type 2. That's lack of information or understanding.”*

*Vivienne, a carer*

Generally participants were realistic about how these could be addressed when considering possible solutions. Ideas which emerged were:



### Outcomes and benefits

Feedback from patients' and carers' suggest that they felt the co-design meetings had been a positive experience. In some cases it provided them with a degree of personal support – sharing experiences with others made participants feel less isolated and fostered a sense of empathy and greater understanding of the issues of others. They appreciated the acknowledgement by the CCG that the patients were the experts in their condition, and that their knowledge and expertise was valued. The participants were also able to take away some practical benefits from the sessions, such as information about local activities and support networks. This was particularly true for recently diagnosed patients.

For commissioners, it provided a sense of reality and enabled them to develop a good understanding of the current situation before turning their attention to providing solutions. It looked for solutions from an end-user perspective, putting patients and carers at the centre of commissioning. This was felt to be pivotal to increasing the likelihood of people using self-care and self-management tools in the future.

### Learning from the project

Although the CCGs came late to the programme, they had already developed their blueprint for the delivery of care to people with long term conditions, and had already started making plans for improving support to diabetic patients and their carers.

Selection of participants was a factor which contributed to the success of the process. Although all the participants were united by their experience of diabetes, the range of ages, circumstances and differences in the severity or longevity of their condition provided a rich insight into how people live with the condition from day to day.

The presence of commissioning managers throughout all events - and particularly clinical directors, who are responsible for shaping services within their CCG - was evidently appreciated by participants. This contrasts with the approach in other areas where CCG representatives joined the last session only. Commissioners from other localities had regretted the absence of clinicians in the co-design meetings. Reflections from participants after the programme indicated that the approach used in Crawley and Horsham was very successful and that positive CCG ownership was a key factor behind the success.

CCG engagement from the CCG is crucial to the success of the co-design approach. Participants clearly appreciated the commissioners' honesty, openness and their willingness to listen, and enjoyed the inclusivity – of being part of a group which had been given the opportunity to contribute and to make a real difference to their local services.

The role of an independent facilitator can be seen as crucial in putting the patients and carers at ease and in creating an open or 'safe' environment, where participants do not feel intimidated by the presence of senior NHS managers who control the delivery of local services. By putting the patients and carers in control, the facilitator ensured participants were able to contribute equally in an atmosphere of mutual respect.

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### Using co-design in the future

The sessions proved to be productive and positive, with participants expressing an interest in being involved further in CCG engagement events.

In order to maintain the momentum and to develop the solutions further, a third set of meetings have been arranged, participants have been invited to attend a third set of meetings with the CCGs, facilitated by the PiC Team.

The aim of the meetings is to co-design a new service for people with diabetes, in which the focus will be on holistic, person-centred care - not just treating the diabetes, but looking at the whole person and the co-morbidities they may also have.

*“The original purpose was to work with the patients to transform the care conversation and patient/professional relationship, but actually it has translated into something much more significant than that!”*

*Sadie, Commissioning Programme Manager*

This is in line with the CCGs’ vision to provide people with a service that will significantly improve care and access for those with diabetes who also have problems with their heart, lungs and/or kidneys. The CCGs want to reduce the number of appointments needed for assessment and management.

In essence, the CCGs are driving a shift away from, “What’s the matter with you?” to, “What matters to you?”

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