

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

Tackling Social Isolation - NHS
Thurrock CCG

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NHS Thurrock 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

Thurrock CCG sits in the East of England and like many CCGs faces challenges around sustainability as a result of an ageing population and increasing demand on NHS services. As an enthusiast of the involvement of patients, people and communities in commissioning, the CCG was interested in the potential of the PiC programme to help it better understand and meet the needs of some of its elderly population struggling with social isolation. Local GPs working together on the 'Everyone Counts' initiative and local voluntary organisations had previously identified social isolation as a significant issue that mattered greatly to older people and impacted on their feelings of health and wellbeing. It hoped work in this discreet area might also help it secure wider benefits in the joint commissioning of more integrated services for specific populations.

Gathering insight and building local understanding

The CCG identified Age UK Essex as the natural voluntary sector partner as they were already in touch with and providing support to the target group of clients. The involvement of Age UK Essex was vital in helping recruit and support clients. They had the local knowledge and networks to build interest in participation and established trust and confidence among potential participants. Without their practical and emotional support to clients, many would have struggled to engage with the programme. They helped create a familiar, relaxed environment where participants felt comfortable discussing feelings and needs that were sometimes quite sensitive and raw.

At a very practical level, the local community transport was also vital in facilitating participation as most participants would have struggled to make the journey to the co design sessions independently. The importance of the service would later be strongly heralded by participants as they often relied on the community transport in order to be able to access opportunities for social interaction.

Two facilitated sessions of insight gathering were held in September and January involving 10 and 3 clients respectively. The first session generated large amounts of rich insight from an often passionate group of participants. Participants were keen to come together for a second session but attempts to run a second session struggled because of reduced numbers as a result of illness or hospital admission and practical concerns about leaving and returning to home in the cold and darkness of the winter months.

What mattered to participants

Participants were very happy to talk about their feelings of loneliness and isolation and there was often strong consensus about what mattered most and how they could be better supported to feel less isolated.

Loss of confidence and esteem:

The lack of opportunities for social interaction left them feeling low in mood and confidence - this was compounded by the feeling of becoming dependent on others for simple tasks – and its impact snowballed.

Difficulty accessing information:

They struggled to find out about what's on, where and when. They bemoaned the loss of local free papers and often struggled to access information through the internet.

Difficulty accessing opportunities for interaction:

They wanted to preserve community transport as a vital service providing a lifeline to opportunities for interaction. They also wanted things like cracks in the pavement to be sorted so that they felt less at risk of falling. They did not see these things as being of interest to 'health authorities' but wanted to stress just how important they were to them.

Choice:

They wanted to be able to access and enjoy activities that had always been enjoyed rather than fitting into what was available or considered age appropriate. There were particular challenges at weekends when opportunities for interaction were reduced and made more difficult because of the availability of transport.

Learning and reflections

Social isolation dwarfed existing long term conditions in terms of impact of on health and wellbeing. Isolation contributed to feelings of being unwell and ultimately led to reduced independence and greater likelihood of accessing NHS services in crisis.

Participants expressed powerful, enduring views about what the NHS should be concerned about. They saw the availability of transport, the quality of pavements, the availability of free newspapers as matters for the Local Authority and not about 'health', yet clearly such issues had a major impact on their feelings of health and wellbeing. Commissioners were able to reflect further on how these concerns and barriers are pivotal, not only to maintaining independence but also in proactively engaging in self-care and wellbeing. These issues can be barriers to accessing health service provision and can contribute to missed appointments and the potential deterioration to older people's health due to the difficulty in maintaining ongoing treatment. The CCG would give further consideration to the type of activities available within the community hub model of support and inclusion.

There was support for the idea of general practice as the ideal location and sense of place for better signposting and peer support because of the perceived demise of locally accessible community infrastructure but there was resistance to further 'burdening' GPs with this responsibility.

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Patients in Control

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