



Improving access to cancer services for Eastern and Central European communities



What needed improving?

The **East of England Cancer Alliances** aim to improve cancer pathways and outcomes for patients. A few members of the existing Patient Partnership Group worked with staff to develop an improvement project using a co-production approach.

Two areas were highlighted as needing improvement:

-  The knowledge and understanding by Eastern and Central European communities of available cancer services, including screening programmes.
-  The referral of patients from Eastern and Central European communities by GPs to secondary cancer services.

The aim is to ensure this community has accessible information about cancer services, including screening, to allow them to make an informed decision about their care and treatment. It was recognised that this community can face difficulties with getting a referral from a GP for cancer diagnostic services, perhaps due to medical records not being held in the UK and/or due to patients feeling it was more convenient to return to their home country and refer themselves to the relevant specialists.

“What she (patient) had to do before the GP, sort of, realised that the condition justified all sorts of things, was to obtain her medical records from Lithuania, translate them into English and pass them on to the GP.”

(Patient Leader, Interview)



Engaging people with lived experience

Recruitment

Previous links had been made with the **Rosmini Centre**, an inclusive community-based organisation providing information, advice and guidance; staff and volunteers at the centre are multi-lingual offering support in English and a number of Central and Eastern European languages. The Rosmini Centre Manager was a key member of the project team. She assisted by recruiting the target population and in the design of events, including identifying other local organisations who support Eastern European people.

“Our approach of going through an organisation (that) has a direct relationship with the community has paid dividends.”

(Programme Manager, Interview)

Engagement events

- A ‘come and see’ event was held at the Rosmini Centre to allow the project team to engage with the target community. Volunteers from the centre provided translation support, to ensure the people with lived experience were able to share their views with accurate interpretation. A charity, Healthy You, supported the event by providing advice to anyone that had any health concerns. Eight people expressed an interest in being involved further in co-producing an improvement and some attendees have continued to work with the project team via email correspondence.

- A listening event, held to coincide with World Cancer Day, focused on cancer prevention and the benefits of screening. Macmillan provided support information on lifestyle changes to reduce the risk of contracting cancer and information on the benefits of screening programmes. The volunteers from the Rosmini Centre asked attendees to share their thoughts and experiences of accessing hospital cancer services.

Although only a small number of people attended the events, due to the in-depth nature of the conversations held, the project team were able to identify key areas for improvement.

Key findings from the events

- Preventative measures such as screening are not well understood or considered important. The ability to easily access diagnostic treatment is considered more important.
- GP appointments: a lack of English is a barrier to making an appointment, difficulty with getting appointments by telephone, difficulty with translation due to some doctors having regional or international accents.
- A lack of information available in community languages about treatment and next steps. No information had been received about screening appointments.
- Information by the NHS to Eastern European patients were either in English or poorly translated. Rosmini Centre volunteers helped these patients understand the meaning.

What has helped so far?



Patient leaders from an existing Patient Partnership Group are driving the project with support from staff. Regular online meetings are held to discuss the project.



Gaining insight from the Rosmini Centre manager ahead of the events was valuable for providing the team with some understanding of the community and their experiences of accessing cancer services.



Partnering with the Rosmini Centre to recruit people with lived experience. The centre has a direct relationship with the target community which helped gain an initial understanding of how to approach people sensitively.



Connecting with existing community and voluntary groups was important for providing support to people with lived experience at the engagement events.



Funding from NHS England helped with both engaging the Rosmini Centre and with people with lived experience by offering incentives (grocery vouchers).



Key challenges and learnings

Ongoing engagement

Following the initial events, it has been difficult to maintain engagement with people with lived experience. Building relationships with communities should be viewed as a long-term process - engagement is necessary before co-production can take place.

Differences in opinions

Differences in views between patient leaders and staff can be difficult. Patient representatives addressed the need to ensure they, as people with lived experience, are heard, and feel empowered to challenge.



“True co-production to deliver service improvements requires trust and a relationship based on understanding each other’s interests. This is more likely to happen when the engagement process has matured and is the next step for this project.” (Programme Manager, Interview)

Next steps

- To conduct further events to gain wider representation of the target population, including another event at the Rosmini Centre and a joint event with Macmillan.
- To co-produce solutions to ensure the learning gathered from these events is used to reduce the barriers to accessing services and drive improvement.
- To develop accessible information about cancer services in different languages.
- To inform system colleagues of alternative ways of engaging with this community, ensuring a flexible and inclusive approach.

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