



Cancer Experience of Care award and Partnership working to improve the experience categories

Surrey and Sussex Cancer Alliance and partners: Sussex ICB, Central Horsham PCN, Dimensions, LDA voluntary organisation, Autek, a video production company that employs disabled people, USHs NHS FT

“What happens next after my cancer screening result was abnormal?”

Working together | Improving together

Background

In Spring 2022 two focus groups held to talk about experience of people with LDA when they attend their cancer screening and barriers accessing the service.

Three LDA support groups provided the feedback:

- LDA Ambassadors group from Grace Eyre LDA charity in Hove
- Impact Initiatives LDA support group, based in East Brighton
- The Dimensions LDA support organisation-Drama group based in Charis Centre in Crawley.

We discussed content, developed a script together with Drama group-people with LDA, and planned all the scenes with the help of Autek.

Dimensions is an incredible organisation that are built with people who have learning disabilities to educate the community through film and drama. This enabled us to get full insight and to work closely with our patients to really tailor this project to meet the needs of our community.

Collaboration

Feedback from the focus groups was shared with the Sussex Health and Care Partnership (ICS) and other colleagues across Surrey and Sussex.

SSCA teamed up with the following organisations and collaborative project was launched in July 22.

- Learning Disability Health Facilitation Team
- NHS Sussex (Integrated Care Board)
- Autek, a video production company that employs disabled people
- Dimensions, LDA charity in West Sussex
- Horsham Central PCN Coordinators
- Horsham Central PCN Practices

The project team agreed to focus on the national cancer screening programme and produce three videos about screening process

- Breast cancer
- Bowel cancer
- Cervical cancer



We created an Annual Health Check video to support people with LDA to attend their AHC where they can be made aware of the importance of cancer screening, using our screening videos.

Co-production with the Drama group

Scripts for videos were developed in co-production with the Dimensions LDA Drama group based at the Charis Centre in Crawley.

We held several meetings with Drama group members. We reviewed readability of the scripts and if the wording is easy for them to understand. It was really helpful to have real time feedback as we could make changes on the day.

Drama group members were acting in all four videos. They told us after filming that they enjoyed being involved in videos, both being filmed and giving feedback about scripts.

The scripts were also clinically reviewed by the clinicians and LDA teams across Surrey and Sussex.



Follow up screening videos for people with LDA

New four videos about Follow Up procedures (colonoscopy, colposcopy, cervical and breast cancer) “What happens next when my cancer screening result was abnormal?” have been completed in July 2023.

We expanded the Project team by inviting colleagues from the United Sussex Hospitals NHSFT, the Royal Surrey Country Hospital NHSFT and new members of the Drama group to participate in the project.

Scripts for new videos have been co-produced again with Drama group members on 22nd March 2023. Gynaecology and Colorectal consultants from St Richard’s hospital UHS NHSFT and Royal Surrey County Hospital NHS FT, LDA nurses teams and the Bowel Cancer Screening hubs’ staff in both Surrey and Sussex reviewed the scripts.



In order to raise awareness and promote LDA nurse’s role, at the end of each video a short narrative about their role was added, explaining also how they can help people with LDA.

Makaton versions of all videos are in development.

Sustainability and impact



Surrey and Sussex
Cancer Alliance

The videos are shared across Surrey and Sussex, regionally and also nationally, as appropriate

The messages and information in videos is transferable for other service users, not only for people with LDA.

We are liaising with various community organisations and healthcare professionals to make them aware of the videos, encouraging them to use videos for their patients.

We have commenced meetings to develop a strategy regarding the implementation and an impact of videos for people with LDA

We have a plan to make sure these videos are sent out and people supported to use them, and mechanisms in place to record how they support people with LDA.

We are expanding video production by engaging people with LDA to become champions for different patient pathways. The first of these is a video that shows a Mental Capacity Act assessment, using colonoscopy as an example.

Lessons learnt

- Communicate well with the ICS colleagues (they provided funds for our videos)-find your allies
- Secure funds first and be clear what you want to achieve
- Establish the project team early by inviting people who will be supportive and committed to the project
- Have regular meetings with the project team (we still have weekly meetings) and give a feedback regarding actions and outstanding tasks
- Rotate chairing at the meetings to give everyone an opportunity to be a Chair
- Engage people with LDA or/and other patient representatives at the very early stages of the project-co-produce always
- Meet face to face-it is important to have personal touch
- Be patient, flexible and understand people's work and other commitments
- Be enthusiastic and positive from the beginning of the project ("We can")
- Follow up the impact of your project and whether Patient Experience was improved (Improvement Action Plan)
- Celebrate with your patient representatives and the project team successes

Follow up videos

Breast follow up video <https://vimeo.com/832083432?share=copy>

Cervical follow up video <https://vimeo.com/832081270?share=copy>

Colposcopy Treatment <https://vimeo.com/832088080?share=copy>

Bowel follow up video <https://vimeo.com/832086347?share=copy>



Questions and answers

