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Summary

Patient involvement in developing patient information

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Nurses

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A UK colorectal cancer service developed a multimedia patient information pathway over two years using patient focus groups to create an interactive website, QR-coded materials, and video resources that address gaps identified in patient surveys.

KEY POINTS

- Initial patient survey showed that while 100% received written and verbal information, 80% sought additional information elsewhere and 80% wanted more visual content such as photographs and videos.
- Four patient focus groups revealed that patients experience anxiety with each phone call, blood test, or scan request, feel overwhelmed by information volume, and value personalized contact with the clinical nurse specialist team and ongoing support for themselves and their families.
- The team created an interactive seven-step cancer pathway accessible via QR codes and a refreshed website, a 10-minute patient journey video with a British Sign Language version, and retained traditional leaflets for patients who prefer them.
- The trust cancer app containing the colorectal pathway had over 26,500 hits with the diagnosis and treatment tile being one of the top three most-used sections, as stated by the speaker.
- The speaker reported that the service was rated outstanding in the caring domain following presentation of this work, and the team is now auditing early-onset cancers to better serve younger patients who prefer digital information.
- Main barriers were time constraints and coordinating schedules for clinical staff already working at full capacity, with consultant availability sometimes requiring six weeks' advance notice.

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