

## Brief communication

# Investigating the use of a patient-facing digital app to support Lynch syndrome carriers in the management of their condition

## Referenced paragraph

Lynch syndrome (LS) is an autosomal dominant inherited cancer susceptibility syndrome, resulting from a pathogenic variant affecting DNA mismatch repair genes. Identified carriers require lifelong multisystem care to manage their condition. The aim of this study is to determine whether a patient-facing digital app could be useful for LS carriers in managing their condition. The app includes an evidence-based personal dashboard score showing how up-to-date users are with their LS management. Key findings included that 15% of participants improved their personal dashboard score in 7 weeks of using the app, and 87% would recommend the app to others.

## Main text

Not all patients with Lynch syndrome (LS) are reviewed regularly to assess their management. They require multisystem holistic management, for example, bowel screening, taking aspirin or a gynaecological review. The Lord Darzi report reflects

a move to more patient-centred care and digital solutions that have the potential to help these patients with their management.<sup>1</sup>

Through Ipsos market research company, we surveyed 106 LS carriers in the UK in an online quantitative survey, consisting of open and closed-ended questions, on what was important to them and whether they would be interested in patient-facing digital solutions.<sup>2</sup> The survey was distributed via email to members of the Lynch Syndrome UK (LSUK) database, and results were analysed by Ipsos. We found that 95% would use such an app to manage their condition and 50% already used health apps at least weekly, for reasons including exercise and support groups.

In response, we developed a patient-facing and patient-entered app supported by NHS East Genomic Medicine Service Alliance, LSUK, Instant Access Medical, Day One Strategy and ESH Solutions.<sup>3–5</sup> The app was developed in English using the Ionic framework hybrid model for both Android and iOS apps in 2022/2023 and involved a patient review panel of three LS carriers (aged 35–60; two females, one male; two Asian, one white British). It is free to download and is updated frequently with new features and the latest information. Users can update their app through the Apple App Store or Google Play Store.

LSUK advertises the app and signposts LS carriers to Professor Julian Barwell for information on the study and informed consent. Only LS carriers are given an access code to use the app to ensure data collected are clean.

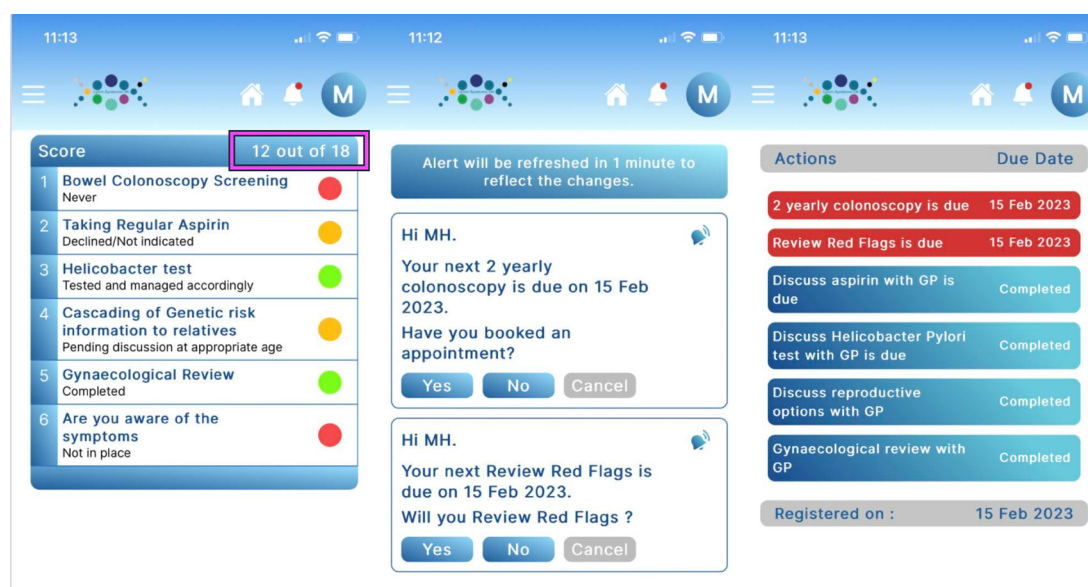
The app aligns with UK Cancer Genetics Group guidelines, addressing

key LS management areas such as bowel screening, aspirin chemoprevention, gynaecological screening and *Helicobacter pylori* eradication.<sup>6</sup> Studies show these measures reduce mortality and delay tumour development in LS carriers, highlighting the importance of appropriate care management.<sup>7,8</sup> These guidelines, alongside red flag symptom awareness and cascading the information to family members, make up six core elements of the personal dashboard.

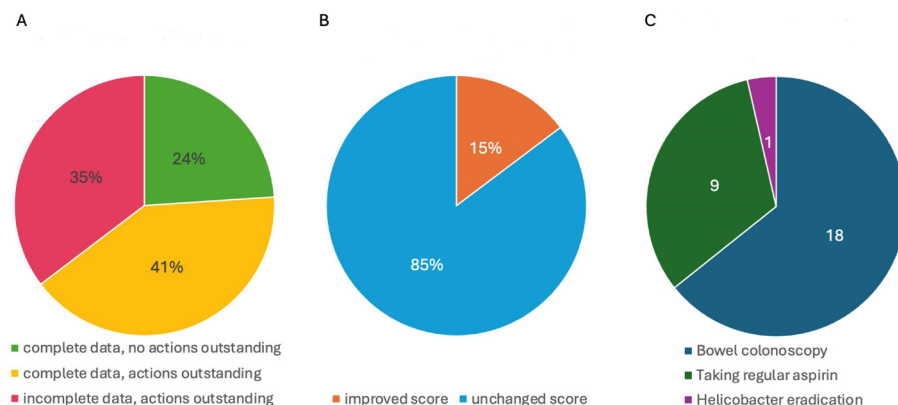
Medical history information is entered by users which scores their management for each element using a traffic light system (figure 1). For example, bowel screening would score 3 (green) if the individual has had a colonoscopy in the last 2 years; 2 (amber) if the individual had a colonoscopy but over 2 years ago; and 1 (red) if the individual never had a colonoscopy. The app generates reminders based on user data, providing a cost-effective, quick and dynamic interface for both patients and healthcare professionals to access a snapshot of a patient's management (see the online supplemental material for more information).

Additional features of the app include guideline updates, letters to general practitioners and family members and useful website links such as LSUK and CaPP3 research trial.<sup>9</sup>

The app data were downloaded every week from 26 November 2024 to 12 January 2025 and analysed using Excel. Participant analytics revealed that of 182 consented participants, 167 input data into the app (92%), and 108 completed



**Figure 1** Screenshots of an example Lynch syndrome (LS) app personal dashboard (left), alerts (middle) and actions (right), with overall personal dashboard score outlined in pink.



**Figure 2** (A) Personal dashboard results: green—participants are up to date with all Lynch syndrome (LS) management; yellow—participants filled in all their medical history information but are not up to date with their LS management; red—participants did not fill in all their medical history information and have incomplete dashboard data and therefore need more support. (B) Percentage of participants with improved scores over 7 weeks. (C) Number of participants who improved their score for each element.

all the medical history data (65%). Of these, 24% have a perfect dashboard score with no actions outstanding and may arguably need less clinical genetics follow-up (figure 2A).

Over the 7 weeks, 15% of participants improved their personal dashboard score in at least one element (figure 2B,C). This reflects an improvement in adherence to the management guidelines. There was no statistically significant association between date of LS diagnosis and personal dashboard score improvement (Fisher's exact test,  $p=1.031$ ). Our colonoscopy data show that 42% of colonoscopies resulted in either polyp removals or cancer detection.

As participants are self-selected and self-reporting data onto the app, our results are dependent on individuals updating their app medical history after an appointment or screening, and there may be ascertainment bias. Furthermore, external factors such as timing of screening and access to hospital appointments may influence the participant analytics results.

An online quantitative survey by Day One Strategy received responses from 82 LS app users. Results showed 87% of respondents would recommend the app to other LS carriers, ranking 'fairly likely' or 'extremely likely' on a 4-point Likert scale, and 73% had an overall positive experience using the app to manage their LS, ranking either 'extremely positive' or 'fairly positive' on a 5-point Likert scale. The most appreciated aspects were 'help to plan my management' (63%) and 'ease of use' (55%). 20% of respondents reported

that seeing their personal dashboard score led to them making a change in their management, correlating with our app analytics of 15% improved scores. The aspects which respondents struggled with most were 'limited or missing features' (40%) and 'user interface (design, navigation)' (20%).

Future feature requests include:

- Updates on new LS research (93%).
- Educational support resources or support (73%).
- Contact details for specialist LS doctors (72%).
- Information on safe medication use (55%).

We propose that patient-facing digital aids will be downloaded, acceptable and helpful in planning and improving care. To ensure effective implementation, additional support must be provided for those struggling with app usage. This is being assessed separately through a user guide. We plan to add further suggested features and track user experience, dashboard scores and app utility over a longer period. We are also continuing research on user interactions with healthcare professionals, which could help expand this technology to other inherited and chronic diseases or pharmacogenetics.

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