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Commentary Article Open Access

Commentary: "Investigating the use of a patient-facing digital app to support Lynch Syndrome carriers in the management of their condition"

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ABSTRACT

Introduction: Lynch syndrome (LS) is an autosomal dominant inherited cancer predisposition syndrome, and the most common cause of inherited colorectal cancers[1]. We conducted a study surveying LS carriers to identify the challenges they face in managing their condition. Based on these insights, we co-developed an app to support LS carriers in staying up-to-date with their management and evaluated if digital solutions could improve care[2]. In this commentary, we explain the rationale behind the app, describe the process of co-development, highlight key findings from the app's analytics, and outline future directions for the app.

Background: Although historically considered a rare disease, researchers estimate that LS affects 1 in 400 people, and only 5% of carriers are diagnosed and aware that they have the condition[3]. It requires lifelong surveillance as the risk of cancers including colorectal, endometrial, prostate, and ovarian cancer can be higher than the general population by an average of 56%, 48%, 24%, and 13%, respectively. The UK Cancer Genetics Group (UKCGG) has published management guidelines that recommend, 2-yearly bowel colonoscopy screening, *Helicobacter pylori* (*H. pylori*) testing, gynaecological reviews for women, aspirin chemoprevention, genetic testing for at-risk family members, and healthy lifestyle advice[4].

The Lord Darzi investigation highlighted that the current NHS App had fallen short of its potential and emphasised the need for technological advancements that would create a "predict and prevent" model for healthcare in England[5]. There is an increased disease burden of long-term conditions and an expectation for general practitioners (GPs) to oversee management[6]. However, the current GP shortage, along with the closing of GP practices in areas of higher deprivation, means that the NHS, at present, is not adequately equipped to meet these needs, and the burden of condition management can often fall upon LS carriers[5,6].

Digital solutions, like patient-facing self-management apps, may encourage patients to keep up-to-date with their management, and have been successful in other disease areas[7]. For example, a smartphone app for diabetes type II was shown to improve medication adherence amongst and medication non-adherent Asian population, with >80% stating the app made them more adherent[7]. Furthermore, a self-management score has been produced to assess self-management behaviour in diabetes patients, which has become a widely used tool by patients and healthcare professionals (HCPs) to help manage their condition and improve communication between HCPs and patients[8]. A mobile app specifically for LS management had not previously been launched in the UK.

95% of UK adults own smartphones, and their mobility means that health apps may be used in any location, at any time, and makes access to healthcare very convenient for a large proportion of society[9]. Additionally, digital healthcare has the potential to minimize ethnic and racial disparities in access to healthcare, when black and ethnic minorities are prioritised for inclusion in design processes[10]. However, digital illiteracy and a lack of trust in IT remain challenges for the uptake of healthcare apps in the wider population, particularly in older individuals[11]. The combined use of healthcare professional visits alongside health apps, as well as access to digital champions who can help and empower individuals using technology have proven to be successful in improving adoption of digital technology[12,13].

Our Study

Our recent study aimed to evaluate the utility of a novel mobile phone app to help LS carriers to manage their condition[2]. Specifically, by analysis of app personal dashboard scores overtime reflecting user adherence to LS management guidelines (n=167), and analysis of survey responses from an online quantitative survey on user engagement and satisfaction with the app (n=82). The study was conducted under University of Leicester ethics (43528-jgb8-ls:genetics&genomebiology) and informed consent was obtained from all survey participants and app users. Information to download the app was disseminated primarily through Lynch Syndrome UK (LSUK) charity and an NHS blog post[14,15].

The app was designed in response to results from an online quantitative pilot survey by IPSOS market research company of 106 LS carriers, which identified 95% of respondents were interested in a LS app, and 81% were interested in co-development[2]. Additionally, the biggest challenges identified in LS carriers were access to a specialist LS doctor (73%), identifying LS champions (50%), and finding information on national guidelines (42%)[2].

The patient-facing LS app, launched in September 2024, set out to act as a personal care record for LS carriers to help them stay up-to-date with their management, and to access information on LS all in one place. We prioritised patient co-design and co-creation throughout, and the large community of LS carriers associated with LSUK was instrumental in providing and communicating with stakeholders. The app has a user completed medical history form that creates the personal dashboard score, highlights the key UKCGG actions to take, and automatically alerts, reminds and follows up for upcoming appointments or management actions due.

The app relies on a personal dashboard snapshot (figure 1) based on the UKCGG LS recommendations, that uses a red-amber-green scoring system. It contains personalised alerts, useful information and research links, as well as letters for GPs and families explaining LS which can be printed or emailed directly from the app. The data is patient controlled, and although participants must consent beforehand, this can be withdrawn by them at any point.

The app's personalised approach hoped to empower patients and improve their scores, thus improving management of their condition.

Despite being identified as key challenges for LS carriers, direct access to a LS specialist doctor or LS champion are not explicit features of the app due to privacy concerns as the app is available for anyone to download. However, information is available on the app such as red flag symptoms or national guidelines that would be provided by a specialist doctor, and links to resources such as LSUK provide opportunities for users to connect with other LS carriers.

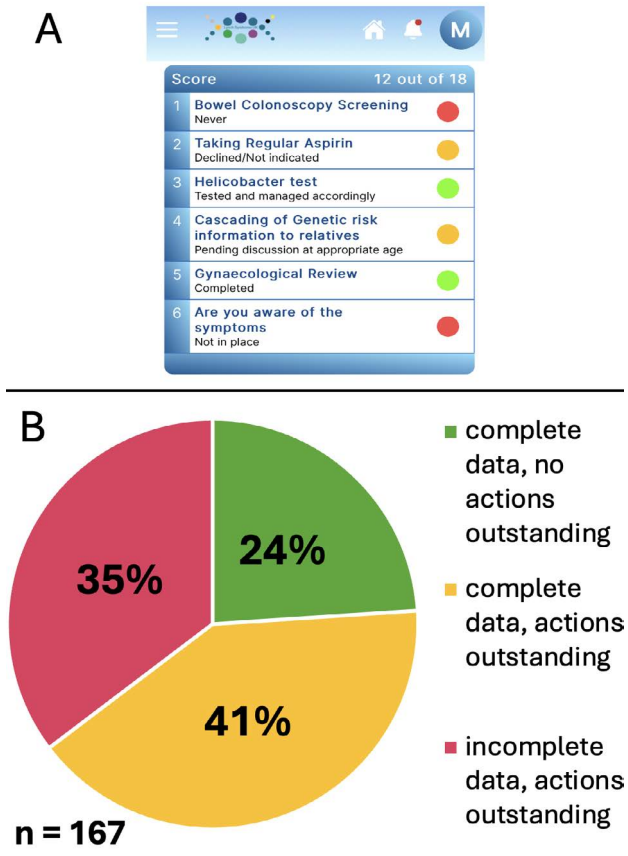

Figure 1. LS app personal dashboard analytics. (A) Image of the LS personal dashboard with a traffic light system that enables LS carriers to manage their condition. Score out of 15 (if male as gynaecological review not relevant) or 18 is given based on user-entered medical history: red = score of 1, amber = score of 2, and green = score of 3. **(B)** App data of 167 users as of 12th January 2025. Users with complete medical history and perfect personal dashboard scores are shown in green, users with complete medical history and actions needed are shown in amber, and users with incomplete medical history and actions needed are shown in red.

User analytics from app data collected from 26 November 2024 to 12 January 2025 showed that 24% of 167 users had perfect dashboard scores, which meant they were completely up to date with their LS management. This was remarkable data; however, we noticed that 35% of the app users had incomplete data, which meant that they had not filled in the entirety of their medical history, so their dashboard scores were not an accurate representation of their management. A subsequent online quantitative survey of 82 app users showed that 71% of respondents agreed that overall, the app is easy to navigate (5-point Likert scale, 'slightly agree' or 'strongly agree'). Therefore, the incomplete data could be attributed to a loss

of engagement, which has been estimated to average at 43% for mobile health apps[16].

We identified that 15% of users had improved their personal dashboard scores in the 7 weeks after the app's launch. This means that an action was taken in-person, then updated in the app, helping them to manage their condition - supported by 20% of survey respondents. Interestingly, 42% of app users that reported having had a colonoscopy, had polyps removed or cancer detected. This is noteworthy when coupled with the fact that 36% of participants reported never having had a colonoscopy, and certain LS variants carry increased colorectal cancer risks as high as 65%[4]. This novel data could be crucial to understanding population dynamics of LS carriers.

In conclusion, our study presents a novel patient-facing app that was co-designed with LS carriers, clinicians, and stakeholders, and indicates how mobile health apps can help to centralise management for conditions requiring multidisciplinary care, support patient self-management, and track real-time critical population data and UKCGG recommended actions. We recognise the importance of management to improve long-term clinical outcomes, and we hope that the LS app can act as a technological model and encourage other digital health solutions.

Limitations and Future Directions

Access to healthcare varies across the UK, and the NHS operates on a 'postcode lottery' system wherein access to treatment, waiting times, and GP numbers vary by region[17]. This can lead to health disparities in which digital solutions can begin to reduce, however digital literacy remains an issue[11], and although there were no significant differences in app usability between age groups, this could be due to the small sample size. To increase the statistical power of our analysis, increasing the number of users is vital to our impact analysis, and assessing the impact of the app is necessary for integration. We have created a schematic (figure 2) that combines the technological acceptance model[18] and the technological integration model[19] which highlights the importance of impact analysis for widespread integration of technologies.

We hope to conduct a formal impact analysis study with an increased sample size to fully determine that the app has a positive impact on LS carriers.

Since Publication

Following the publication of our paper, we collected survey responses and created a list of changes to be made to the app. This list was reviewed at 2 Patient Review Panels in April 2025, then prioritised for an updated version of the app which was released on 16 June 2025 (figure 3). Consent was embedded into the app, which streamlined the access code sign-up process, colour changes were made to the apps interface, language change options were added, and the scoring system was explicitly stated.

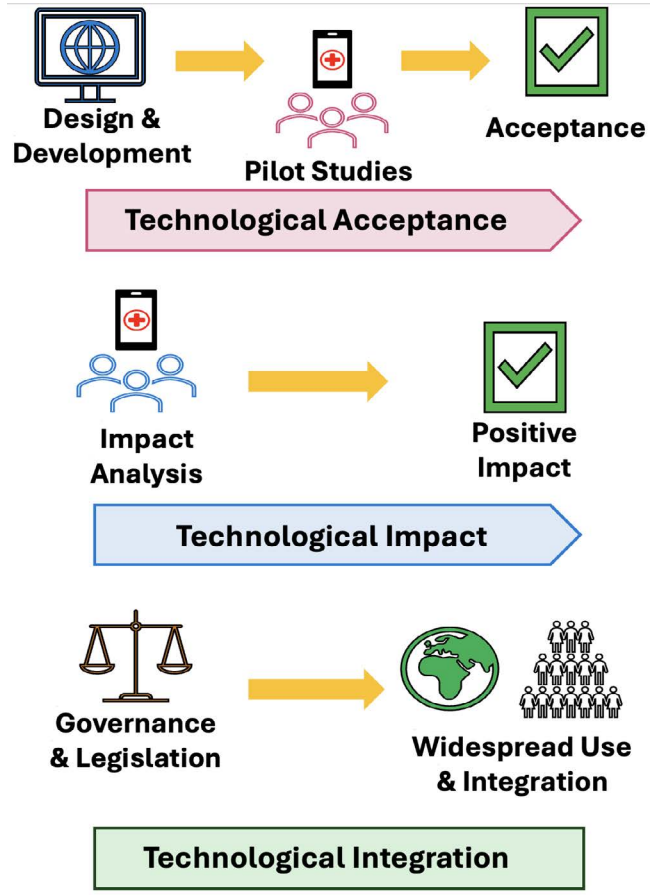

Figure 2. Route to integration of the LS app. The pipeline of technological acceptance to integration, which centralises the impact with a focus on mobile apps.

Subsequently, a second wave of the survey was released on 27 June 2025, and we received 56 respondents – 35 of which had completed both surveys. Analysis is ongoing, which we hope will continue to inform the patient-led evolution of the LS app.

Conclusion

In conclusion, our study presents a novel patient-facing app that was co-designed with LS carriers, clinicians, and stakeholders, and indicates how mobile health apps can help to centralise management for conditions requiring multidisciplinary care, support patient self-management, and track real-time critical population data, and UKCGG recommended actions. We recognise the importance of management to improve long-term clinical outcomes, and we hope that the LS app can act as a technological model and encourage other digital health solutions.

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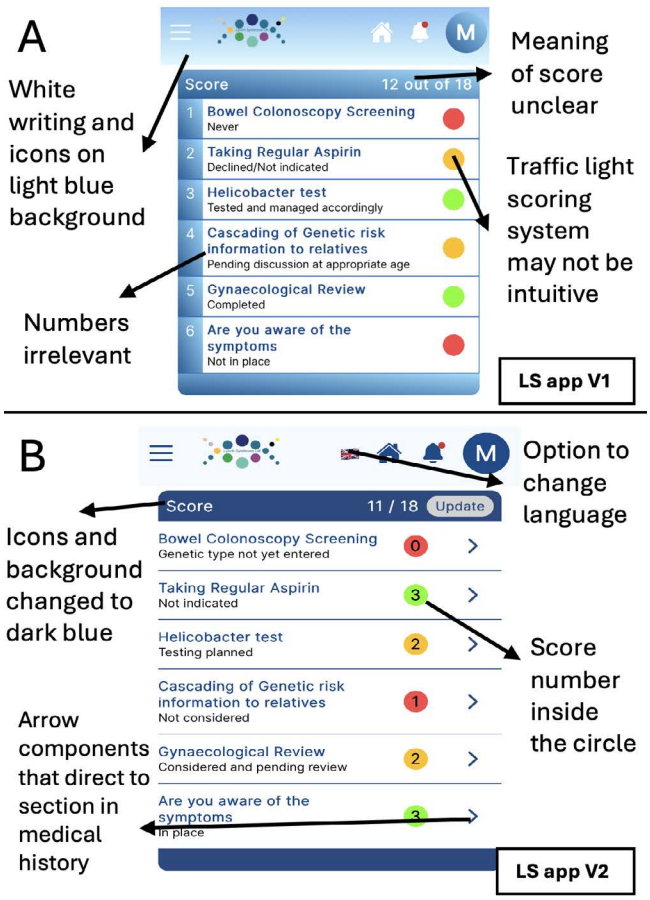

Figure 3. Comparison of the personal dashboard user interface. (A) Labelled image of some of the negative aspects of version 1 of the LS app. **(B)** Labelled image of the main changes to version 2 of the LS app.

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Conflict of Interest Statement

Madonna Jonhera, Megan Hopkinson, and Dr. Stan Shepherd declare no conflicts of interest.

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