Psycho-Oncology

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ORIGINAL ARTICLE OPEN ACCESS

'I Live With Lynch. Cancer Worry Ebbs Into the Background, Then Something Brings It to the Fore.' A Qualitative Interview Study Exploring How Lynch Syndrome Carriers Make Sense of Their Cancer Risks and Implications to Support Decision Making

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Received: 26 June 2024 | **Revised:** 9 August 2024 | **Accepted:** 31 August 2024

Funding: Funding for this project was provided by Cancer Research UK Catalyst Award CanGene-CanVar [C61296/A27223].

Keywords: cancer | decision making | genetics | oncology | patients | psycho-oncology

ABSTRACT

Background: Lynch syndrome carriers ('carriers') are presented with complex, emotionally laden choices regarding management of increased genetic cancer risks. Decision aids encourage active involvement in values-based health decisions. This paper aimed to address the research question: How do Lynch syndrome carriers make sense of their chances of developing cancer, and what are the implications for providing support with decision making about genetic cancer risk management?

Methods: Adult carriers were recruited through a genetics service or involvement with Lynch Syndrome UK. Semi-structured interviews explored lived experiences of carriers' access to care with a focus on decision support. Themes were constructed using framework analysis. These were developed into a conceptual model with recommendations for codevelopment of improved information and support including a tailored decision aid to complement integrated healthcare.

Results: Twenty participants included 12 women and eight men, half with a history of cancer. Six overarching themes were: (1) finding balance with Lynch; (2) living 'on higher alert'; (3) managing uncertainty: 'I've thought about it a lot'; (4) burden of responsibility: 'It's on me'; (5) access to joined-up care and support: 'There's something missing'; and (6) influence/pressure from others.

Conclusions: This qualitative interview study provided in-depth insights from Lynch syndrome carriers about their lived experiences, informed by their values. Recommendations to empower carriers to make sense of genetic cancer risks and support

For a complete list of the CanGene-CanVar Patient Reference Panel and International Lynch Decision Aid Stakeholder Panel, see the Acknowledgements section.

decisions included accessible, trusted information, educated healthcare professionals, shared decision making, and joined-up integrated care pathways complemented by tailored decision aids.

1 | Background

There are four types of Lynch syndrome ('Lynch'), one of the most common genetic cancer predispositions [1]. Lynch is dominantly inherited and occurs due to a germline pathogenic variant in a DNA mismatch repair (MMR) gene: *MSH2, MLH1, MSH6* and *PMS2,* or due to inactivation of *MSH2* caused by partial deletion of *EPCAM*. Lynch syndrome carriers ('carriers') are *path_MMR* variant carriers, but may never develop cancer, especially with *PMS2* which confers lower risks. Clinical management guidelines are gene-, gender- and organ-specific [1–3] (https://www.ukcgg.org). Carriers with increased genetic cancer risks face time-sensitive decision-making which is highly personal and emotionally laden [4, 5]. Complex choices include surveillance, risk-reducing intervention, lifestyle modifications, and talking to family. If cancer develops, Lynch could introduce additional decisions about precision medicine [6].

Genetic counselling helps people 'understand and adapt to the medical, psychological and familial implications of genetic contributions to disease' [7], an exemplar of shared decision-making [8, 9]. Genetic testing has steadily increased without a corresponding growth in the genetics workforce. This, along with rapid results needed to inform treatment, has led to testing moving into the 'mainstream' with point-of-care genetic testing in oncology [10] and development of streamlined digital platforms for information [11] and consent [12]. Most people cope well with genetic testing, although some benefit from additional counselling due to anxiety, depression or cancer worry [13]. Referral to genetics services should take place for psychological support, coordination of multi-disciplinary care and facilitation of familial testing [14].

Gaps in support to manage increased cancer risks have been identified through recent qualitative research studies highlighting issues such as poor information provision and uneducated healthcare professionals, resulting in a personal burden and negative psychological impact on carriers [5, 15]. These studies have been small and located outside the UK. Previous research has focussed on access to care or specific decisions. There is limited knowledge about carriers' holistic experience of care pathways and how well information and genetic counselling empowered them to self-manage and make decisions about several Lynch-related cancers that become relevant at different stages of life.

Written and digital resources can be helpful following genetic testing [16] to complement discussions with healthcare professionals. Short leaflets are usually provided but are often too complex, lack personalisation and are not codesigned with 'patients' and other experts [17] nor evaluated by underserved populations [18]. Decision aids go beyond simple leaflets to encourage active involvement in shared decision-making in line with values and preferences (see https://decisionaid.ohri.ca). Decision aids adhering to IPDAS (International Patient Decision Aids Standards) can reduce decisional conflict and improve knowledge, understanding and satisfaction [19]. The original research presented here was part of a larger programme (https://www.cangene-canvaruk.org) to codevelop a personalised information hub and decision aid called Lynch Choices [20, 21] (Figure 1). Findings from this study added value and provided in-depth understanding of carriers' experience to inform optimisation of the decision aid to ensure it was meaningful, engaging and fit the context in which a diverse group of people would use it.

Research question: How do Lynch syndrome carriers make sense of their chances of developing cancer, and what are the implications for providing decision making support about genetic cancer risk management?

2 | Methods

2.1 | Public Involvement

A Patient Reference Panel established to support the programme of research reviewed study materials before the ethics application (Table S1 shows examples of how feedback was prioritised). The study received ethical approval from University of Southampton, National Research Ethics Service and Health Research Authority (REC 22/NI/010, IRAS 312473). Consolidated Criteria for Reporting Qualitative Research [22] ensured comprehensive reporting (Table S2).

2.2 | Study Design

A qualitative design was chosen to learn directly from lived experiences to address the research question. Perspectives of carriers were prioritised. Rich data was sought to explore varied experiences embedded in situational context including cancer diagnosis, recovering from surgery and taking action to lower cancer risks while balancing other life priorities such as looking after children. Interviews included a semi-structured component about experiences of living with Lynch (reported here) and a think-aloud component focussed on perceptions about the prototype decision aid (reported elsewhere). The Person-Based Approach was used to guide codesign of Lynch Choices™ as an effective set of methods for developing context-sensitive behavioural health interventions by combining qualitative research and stakeholder engagement [23] (Figure 1).

2.3 | Recruitment

Eligible participants were aged 18 or older and self-reported as Lynch syndrome carriers. A Research Practitioner confirmed *path_MMR* variants by screening a clinical genetics database. The researcher (K.K.) is Lead Genetic Counsellor at this service

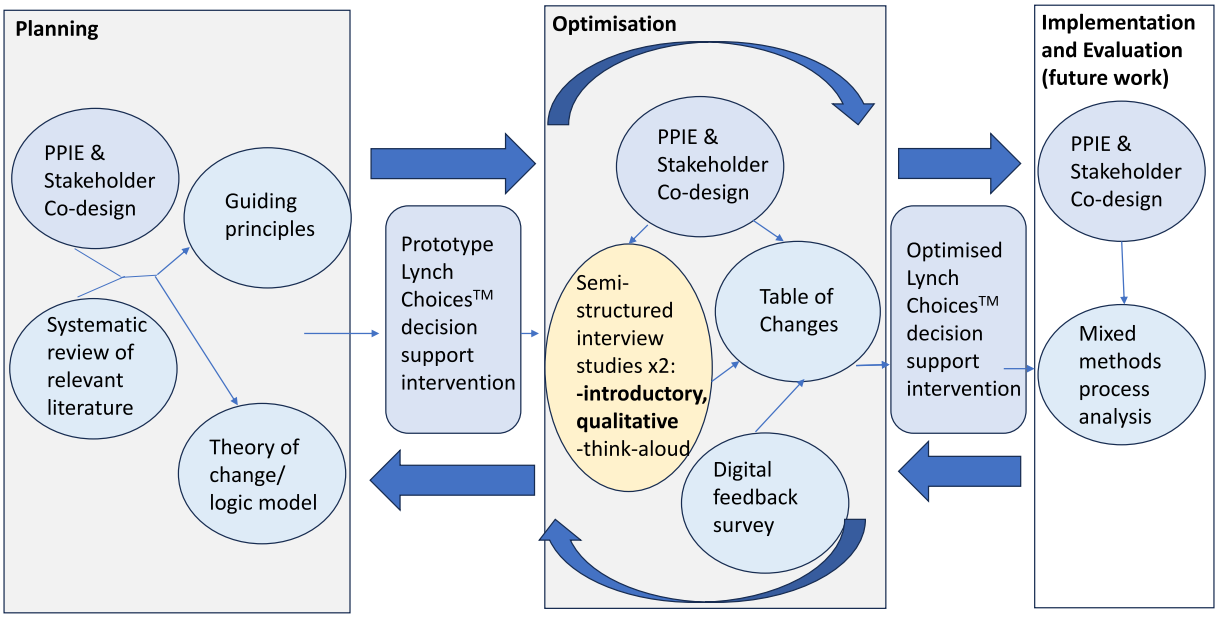

FIGURE 1 | Schema showing the overarching CanGene-CanVar programme of work to codesign a decision aid with patients and other expert stakeholders for genetic cancer risk management, guided by the Person-Based Approach. The study presented here includes the **introductory, qualitative** interviews shown in the yellow circle of the optimisation phase of codesign of the complex health intervention, Lynch Choices.

and invited clinicians to invite eligible patients opportunistically, including purposive sampling to include men. Additionally, a convenience sample included Lynch Syndrome UK (https://lynch-syndrome-uk.org) members who had participated in an unrelated public engagement workshop and agreed to future contact. They were asked during interviews to confirm they were *path_MMR* carriers. Standard invitation materials were used (Supporting Information S1), with at least 24 h to review these before scheduling the interview. Recruitment was completed when no more significant findings were identified [24].

2.4 | Data Collection

Interviews were offered using video, telephone or in person. A semi-structured guide was used (Supporting Information S1). Audio recordings were transcribed verbatim using automated software followed by manual correction and were pseudo-anonymised. Demographics were collected along with questions to assess health literacy [25], since this can affect knowledge and effective use of decision aids [26]. These questions were asked at the end to allow rapport-building.

2.5 | Data Analysis

Framework analysis [27] was used, starting with familiarisation to develop and apply an analytical framework and chart exemplar quotes across themes and subthemes. This strategy provided an 'intuitively structured overview of the summarised data' [27]. Themes were coded inductively, with the researcher finding 'new patterns of meaning' [28]. Coding was completed by one researcher (K.K.) followed by discussion with the team (K.M./B.F./L.T./D.E./C.F.). Findings were reviewed by co-authors (E.K.B./M.J.E./H.H./K.H./K.S.) who contributed to development and finalisation.

Positionality of the researcher (K.K.) is acknowledged, as a person with white ancestry, in a position of power in genetic counselling with a desire to improve care and decision support. The researcher conducted interviews as a PhD student and clinical queries were directed back to health services.

One researcher (K.K.) mapped themes to show the level at which they were operating. A conceptual model was developed to provide a visual representation of key themes, variables, participants and interrelationships. This enabled the researcher, who understood care pathways, to develop recommendations to better support and empower carriers.

3 | Results

Twenty carriers were interviewed: 10 from the genetics service and 10 through Lynch Syndrome UK. An additional 16 were invited through the genetics service but did not respond, and two consented but did not schedule an interview, giving an overall uptake of 20/38 (52.6%). Interviews were conducted via video (n = 19) or in person (n = 1) between August 2022 and February 2023 and lasted 46 min on average (range: 26–61 min).

Characteristics of the total sample are presented in Table 1, with individual characteristics in Table 2. Twelve females and eight males participated (age range 18–70 years). Half had a cancer diagnosis (n = 10, including n = 8 bowel). Participants had white British (n = 14, 70%), other white (n = 2, 10%) or Indian/Asian ancestry (n = 4, 20%) and lived in different areas of England and Scotland. Time elapsed since genetic testing varied from 2 months to over 20 years. Health literacy was high, with

TABLE 1 | Characteristics of total sample of interview participants, consisting of $n = 20$ Lynch syndrome carriers.

	Number	% of total participants
1. Source of invitation (participants could choose one or more option)		
a. Genetics service	10	45%
b. Cancer/oncology service	3	25%
c. GP	0	0%
d. Lynch Syndrome UK	4	40%
e. Bowel Cancer UK	0	0%
f. A friend or family member	0	0%
g. Other (please state here):	5	23%
2. Age (years)		
18 to 25	1	5%
26 to 40	6	30%
41 to 60	11	55%
61 to 70	2	10%
Over 70	0	0%
3. Education (left full-time studies)		
Before finishing school	1	5%
After finishing school	6	30%
After finishing university	8	40%
After postgraduate studies	5	25%
4. Gender		
Male	8	40%
Female	12	60%
Other/Prefer to self-describe: (Optional to add text):	0	0%
Prefer not to say	0	0%
5. Ethnic group		
Black Caribbean	0	0%
Black African	0	0%
Black other	0	0%
Bangladeshi	0	0%
Chinese/South East	0	0%
Indian	2	10%
Pakistani	0	0%
White British	14	70%
Any other white	2	10%
Asian	2	10%
Other	0	0%
Prefer not to say	0	0%
6. Cancer history		
No	10	48%
Bowel (colon) cancer	8	38%
Endometrial (womb/uterus) cancer	0	0%
Other (please state here):	3	14%
7. Post code (or country if outside the UK)		
UK post code	19	95%

(Continues)

TABLE 1 | (Continued)

	Number	% of total participants
Not answered	1	5%
Other country	0	0%
8. Access requirements		
Yes	2	10%
Not answered	1	5%
No	17	85%
Questions to assess health literacy:		
9. How often does someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?		
(1) Always	0	0%
(2) Often	0	0%
(3) Sometimes	0	0%
(4) Occasionally	2	10%
(5) Never	18	90%
10. How confident are you filling out medical forms by yourself?		
(1) Extremely	13	65%
(2) Quite a bit	6	30%
(3) Somewhat	1	5%
(4) A little bit	0	0%
(5) Not at all	0	0%
11. How often do you have problems because you find it difficult to understand written information about medical conditions?		
(1) Always	0	0%
(2) Often	0	0%
(3) Sometimes	3	15%
(4) Occasionally	8	40%
(5) Never	9	45%

few requirements to assist understanding of medical information. Sixty-five percent (13/20) had completed higher education.

Six themes were constructed from interview data, detailed below. Table 3 summarises themes, subthemes and exemplar quotes, with additional quotes in Table S3.

3.1 | Theme 1. Finding Balance With Lynch

All participants had a personal and/or family history of cancer, with variation in how easily genetic testing was obtained. Even with knowledge of a genetic variant in their family for years, they could be taken aback by the news of their own diagnosis:

> *It was really surprising...but I knew it was 50/50% '[chance].'* (p001) Test results had immediate impact on perspectives about the future, with realisation that many lifestyle choices could influence cancer risk and may become more important: '*It was not until that call it was like... this is real for me, this really changes the way things are... that's a very different life I need to lead.' (p001)* Some participants used positive framing, *'I'm not gonna say it's a blessing, but it's... not a bad thing' (p006)*, recognising that knowledge could grant power to control cancer risks. Normalisation coping techniques were employed, for example pointing out that all families have genetic variants, some with more serious health consequences or less management options than Lynch: *'We all have hundreds of broken genes and the fact that some of mine have been identified and there's something' I can do about it is great.' (p006)*

3.2 | Theme 2. Living 'on Higher Alert'

Genetic testing added extra complexity to a cancer diagnosis: *'I had no idea [about] Lynch... you don't look into these things... unless you become one of it. And then I lived with that thought of*

TABLE 2 | Characteristics of individual interview participants (n = 20 Lynch syndrome carriers).

Participant	Age range (years)	Gender	Gene	Previous diagnosis of cancer	Type of genetic testing	Approximate time since Lynch diagnosis
P001	26 to 40	Female	*MLH1*	No	Predictive	2 years
P002	61 to 70	Female	*MSH6*	Yes	Diagnostic	2 years
P003	41 to 60	Female	*MLH1*	Yes	Diagnostic	3 years
P004	26 to 40	Female	Unknown	Yes	Predictive	10 years
P005	41 to 60	Female	Unknown	No	Predictive	15 years
P006	41 to 60	Male	Unknown	No	Predictive	14 years
P007	41 to 60	Male	*MSH2*	Yes (three)	Diagnostic	22 years
P008	41 to 60	Female	*MLH1*	Yes	Diagnostic	6 months
P009	61 to 70	Female	*MLH1*	Yes	Diagnostic	1 year
P010	41 to 60	Female	Unknown	No	Predictive	10 years
P011	26 to 40	Male	*MSH2*	No	Predictive	6 years
P012	41 to 60	Male	*MSH2*	Yes	Diagnostic	15 years
P013	26 to 40	Male	Unknown	No	Predictive	8 years
P014	41 to 60	Male	Unknown	Yes (three)	Diagnostic	20 years
P015	41 to 60	Male	*MLH1*	Yes	Diagnostic	6 months
P016	26 to 40	Female	Unknown	Yes	Diagnostic	1 year
P017	41 to 60	Female	*MSH6*	No	Predictive	6 years
P018	26 to 40	Female	Unknown	No	Predictive	2 months
P019	18 to 25	Female	Unknown	No	Predictive	2 years
P020	41 to 60	Male	Unknown	No	Predictive	15 years

cancer... the most agonising because I'm thinking, am I dying <laugh>?' (p008) Post-treatment, participants could have benefited from more timely information and support, especially to reassure them that carriers can live a long, healthy life: *'It kind of puts you on higher alert... you don't want to get lost or forgotten.' (p016).*

3.3 | Theme 3. Managing Uncertainty: 'I've Thought About It a Lot'

Actively taking control could help carriers to manage uncertainty about the looming risk of developing cancer. Actions included surveillance, symptom awareness, risk-reducing interventions or lifestyle changes. However, there was awareness that they might be adhering to advice with unproven impact: '*I dunno if there's any science behind that, but I think [lifestyle changes] will help.' (p011)* Lowering cancer risk was important enough for some participants to give up things they enjoyed, and prioritise health: *'I've thought about it a lot and I made huge changes ... I'm quite careful about what I put into my body' (p011); 'I run a strict diet and I work out.... I try to get at least 8 hours sleep. I really am in control of my microbiome.' (p014)* Others described feeling that they should move forward but had not done so due to competing priorities, which could leave them feeling guilty or preoccupied: '*I think I do need to [have a hysterectomy]. It's just that I haven't. I've been so busy.' (p016)* Barriers contributing to avoidance also included quality of life concerns (menopause, fertility, aspirin side effects) and lack of trust (uninformed healthcare professionals, unclear aspirin dose, incorrect HRT advice).

3.4 | Theme 4. Burden of Responsibility: 'It's on Me'

Carriers had to be proactive to ensure healthcare professionals were informed: *'There was a huge knowledge gap. I was educating them [General Practitioners (GPs)].' (p001)* GPs were approached for advice, referrals and aspirin/HRT prescriptions but were not informed and ready to provide these: *'GPs haven't got a clue. They haven't even heard of [Lynch]. They have absolutely no idea.' (p017)* This could damage trust in the system. There was a personal burden to be in control of their health: '*I struggle to... get someone to say, Oh, I know all about that. I know where you're coming from. I know what we need to do.' (p002) 'If there's not clear, concise communication... if there's a breakdown, that just adds to a bit of anxiety or a bit of pressure, or you feel like you are the one that's always taking the lead... it doesn't feel like a real partnership at times.' (p002).*

There was also frustration about lack of knowledge about Lynch in the community. Participants wanted support from loved ones, but again had to ensure their situation was understood so they were not made more anxious by reactions: *'You have friends around you, that circle that are equally... uneducated... The alarm... it's like adding fuel to fire <laugh>.' (p008).*

Tailored support was insufficient, especially at vulnerable times: *'Nobody's called me to see how I am... Once you leave the hospital... you're sort of signed off... nobody comes near you 'cause they've got new people.' (p009) 'Any sort of specific guidance is critical, which is tailored to the individual... [it] has been missing.*

TABLE 3 | Summary of six overarching themes constructed from interview data, including descriptive summaries, subthemes and exemplar participant quotes. Additional quotes can be found in Supporting Information S1.

Overarching themes, with descriptive summaries	Subthemes	Exemplar participant quote selected from $n = 20$ interview transcripts
1. Finding Balance After a Diagnosis Of Lynch. Lynch syndrome carriers may have lived with cancer in the family for years and worried about being affected. A genetic test result identifying Lynch could be felt as a relief, something to get used to and be aware of but not let it take over due to the need to balance with other life priorities	1.1 Incorporation into personal identity	'I am ok in the mental sense of things. I'm ok with where I am now. Now it's Lynch syndrome.' (p008)
	1.2 Cancer worry: From 'panic' to 'back of my mind'	'The interesting thing is that having now been living with the knowledge that I have this mutation... it kind of just sometimes ebbs away into the background a little bit. Something might happen which might then kind of bring it to the fore.' (p015)
	1.3 Personal and family history of cancer	'I kind of made an assumption ... I looked through the family and you could kind of see... actually if it is in the genes... there was a lot of cancer within the family.' (p018)
	1.4 Impact of results disclosure	'When the consultants came in I knew... this was going to be some type of different news. I know this is going to sound a bit weird, but it was a relief to know.' (p002)
	1.5 Concern for children and relatives	'It's an immediate reaction that I wonder if my son has it. I didn't know how to tell my parents, because they're going through this horrible thing with my brother. And my dad felt guilty for that, and I was like don't want to give him further guilt. So, it was just a lot of information and just dealing with the emotion of other people as well.' (p001)
2. Living 'On Higher Alert': The experience of being diagnosed with cancer and how they were told was impactful for Lynch syndrome carriers. Some were expecting to develop cancer due to their family history and others were surprised, but they all found ways to cope and adjust. This was difficult but also brought gratitude for survival and awareness that things could have been worse. Lynch provided a genetic reason why cancer occurred, replacing previous theories about lifestyle or environmental factors.	2.1 Getting a diagnosis	'[The GP] gave me an internal and straight away she said, I can feel something. I Feel a mass, I need you to go into A&E because if you don't, I can refer for you for a CT, but it's gonna be... I don't want you to wait that long. So go down to A&E then it's panic mode, obviously.' (p003)
	2.2 Recovery and adjustment	'I'm just on these drugs... it's just like having permanent chemotherapy. I do get hot flushes... But apart from that, I really wouldn't know that there was anything wrong with me. I must be the luckiest human being alive. And I'm certainly the wealthiest human being alive <laugh> not materially, but certainly because of what I know. What I've experienced and the fact that I'm still here.' (p014)
	2.3 Clarifying the cause of cancer as genetic rather than environmental	'My mum was not in the healthiest shape in her life... I think that maybe some of her drinking or... she was slightly overweight, if that might have... it's very easy to see the worst so I can see where some that's coming from. (p019)

(Continues)

TABLE 3 | (Continued)

Overarching themes, with descriptive summaries	Subthemes	Exemplar participant quote selected from $n = 20$ interview transcripts
3. Managing Uncertainty: 'I've Thought About It a Lot.' Participants accepted that as Lynch syndrome carriers they needed to be more aware and prioritise health. They might have pursued risk-reducing surgery or made big or small lifestyle changes to lower their chances of developing cancer, such as exercising, avoiding alcohol, eating less red meat and more fibre.	3.1 Taking action to lower chance of getting cancer	'All I was interested in was what could be done. Whether your lifestyle's ok. If there's anything you need to change in your lifestyle.' (p002)
	3.2 Reassurance from being part of a programme	'I kind of trust that I'm under... I'm being scanned routinely, that I will have a colonoscopy for the rest of my life. So, I trust that that is covered. I've actually read that people that have Lynch syndrome and regular colonoscopies do better than those that don't have Lynch 'cause they don't get checked. So, I feel like that base is covered.' (p016)
	3.3 Prioritising decisions according to personal situation	'Personally, I think in my head I am quite balanced and I'm able to organise and prioritise... in this situation, I just needed to get back to full f health [before deciding about surgery] and not have all of these dangling stresses, because it just takes the life out of you... Whatever it, you know, even if I'm mutated into something else altogether, I have no problem as long as I'm there for [my son].' (p008)
	3.4 Helping others	'I'm one of these people who tends to give rather than receive. I'm very much a doer rather than a talker.' (p014)
4. Burden of Responsibility: It's on Me. Lynch syndrome carriers encountered GPs and others who did not know about Lynch, which was frustrating. Although there was some comfort from being part of surveillance programmes, it was recognised that being proactive and symptom-aware was also a personal burden they needed to bear to feel confident about cancer prevention or earlier diagnosis.	4.1 Need to educate others about Lynch	'Most people don't know what [Lynch] is. You know, you tell people, I've got diagnosed with a genetic condition. They go, oh my God, like what is it?' (p019)
	4.2 Need to be proactive about access to care	'Making sure regular screenings are up to date. I was due to have a colonoscopy and I had to make several phone calls to ensure that it was a camera pill only to find out that it wasn't.' (p002)
5. Access To Joined-Up Care And Support: 'There's Something Missing.' Lynch syndrome carriers understood the need to prioritise urgent cases in a resource-stretched healthcare system but would have appreciated more joined-up care with clear information and clinicians knowledgeable about Lynch. Participants turned to charities, patient groups and social media for unmet needs but would have valued expert help navigating trusted sources.	5.1 Integrated care pathways: From GP to specialists to Clinical genetics	'It was reassuring to know that I could ask [genetic counsellor] because I think there was a time where I couldn't fix up a date for colonoscopy. I was certainly anxious about that 'cause I just wanted to get it sorted and I emailed. And it happened really quickly. And that was just reassuring... just that to know that there is an in like that.' (p011)
	5.2 Charities and peer support	'I found Lynch syndrome UK. I joined the group and then I started going to the annual conferences.' (p005)
	5.3 Up-to-date, trusted information and expert research	'I did get information from leaflets... but other than that it was fairly limited. To be honest... it was almost self-guided. There was signposting... but that was pretty much

(Continues)

TABLE 3 | (Continued)

Overarching themes, with descriptive summaries	Subthemes	Exemplar participant quote selected from $n = 20$ interview transcripts
		it. I've done various kind of Google searches for anything that may be of interest and curiosity a little bit more ... But to have it all in one place would be really helpful.' (p013)
	5.4 Personalised, shared decision making	'My problem is my thoughts about the menopause. And because I've struggled so much with my mental health and I've got to a good place now, I don't want to do something that's gonna trigger me to then suffer with my mental health again.' (p018)
	5.5 Navigating delays in care	'I went to the GP. Originally, I was told, oh, it's bad luck, and I just pursued it and I said, I'm sorry, that's not bad luck [about family history of cancer].' (p017)
6. Influence/Pressure From Others: Lynch syndrome carriers were influenced by family and those close to them as well as healthcare professionals, whose support or pressure was understood to come with good intentions but was not always delivered in the most helpful way. Other carriers often provided the most relevant or persuasive influence on decision-making.	6.1 Support	'I just talked to my family.' (p017)
	6.2 Pressure	'I do have to say that I do feel under pressure whenever I talk to my gynaecologist, because there's always that question: Have you decided yet [about risk-reducing hysterectomy]? (p005)

(p012) Independent research, charities, peer support groups, and social media filled a gap for some that was not met by the NHS: *'There's a lot more access to online talks and things... I've watched Zoom talks or YouTube that people have linked to.' (p020).*

3.5 | Theme 5. Access to Joined-Up Care and Support: 'There's Something Missing'

A common theme was the need for lifelong, joined-up care: *'With Lynch there's so many different types of kind of cancers and... you don't really have one person looking at you end-to-end...' (p001)* Holistic care was challenged by lack of communication between services:

> 'I *felt like maybe there's something missing and it's no one's fault. Like my colorectal surgeon is not an HRT expert.' (p003)* Colonoscopy surveillance was sometimes the only regular touchpoint, leaving people feeling uneasy about what else they should be doing: *'Apart from those colonoscopies, there's nothing else going on between myself and a hospital or any kind of medical body. I feel like the rest of it is on me.' (p004)* Some did not feel safely looked after, with anxiety about falling through the cracks: *'Sometimes it's easy to get complacent and ... allow the NHS [National Health Service] to cancel appointments... That part of it I think is a little bit difficult'. (p015)* Clinical Genetics played an important role as anchor and guide: *'If I ever have any questions or anything, my first port of call is always the genetics service.' (p017).*

Participants stressed that information should come from a central, trusted source and would have valued more signposting and guidance: *'There's so much information out there... you want to know that there's somewhere you can go* that is *true and reliable and there's knowledge behind it. Safe place to look.' (p018).*

3.6 | Theme 6. Influence/Pressure From Others

Family, friends and others were consulted for guidance and reassurance, which could encourage a positive outlook: *'My uncle... he's very much like, nothing to worry about... it's quite positive' (p011).* Their counsel also helped provide perspective and cope with feelings like anxiety and cancer worry: *'One of my best friends... said... we've all got to die of something... at least you know ... what to look out for ... You'd rather know than not know.' (p011)* When they had dealt with initial emotions and were ready to move on and think about decisions, carriers were influenced by role models in their family who had made choices: '*I take aspirin because my mum was taking aspirin, so I kind of just jumped on the bandwagon.' (p018)* Sometimes they felt pressure to comply with expectations, or stop others

worrying about them dying of cancer, especially in the context of loss and grief within the family.

Participants expected to be consulted about irreversible decisions such as surgery:

> *'The surgical team were keen... I had to keep reiterating that I didn't want the stoma... I can see their point of view... it reduces the overhead of managing me, but... I felt like they were possibly trying to nudge me in a direction I didn't really want to go.'*
>
> (p007)

Some felt pressure due to urgency of treatment or the forcefulness of surgeons' opinions which resulted in decisions made in a blur, without time for considered deliberation: *'I do feel that I'm being left out in the dark.... It was all go, go, go with the operation and the chemo and everything else.' (p009)* They wanted individuality to be considered and most needed more time, information, and to consult important influencers in their lives. However, this was preference-dependent, with one participant who declined extra referrals or support groups and took a self-led approach to managing wellbeing: *'I'm not someone that really needs a lot of support... I'm pretty level-headed. I feel like the care that I had for my surgery... and from my oncologist was enough.' (p016).*

3.7 | Theme Mapping

Six themes were developed into a conceptual model to show the levels in the integrated healthcare system at which they operated. Figure 2 displays interrelationships between inductively developed themes, levels of care and recommendations to better empower carriers to make sense of their cancer risks and support decision-making. Information, support and care were accessed in a distributed way [29] over time and space as carriers negotiated complex decisions that were age, organ-gender-, time- and context-specific. This included the individual level (personal burden), through important relationships (friends, family and Lynch peers) and healthcare professionals. Implications were considered for codesign of a tailored information hub and decision aid, especially needed due to scaling up 'mainstreamed' genetic testing.

4 | Discussion

Qualitative interviews provided insight into the lived experiences of carriers, focussing on decision support. Participants expressed understandable frustration with delays accessing the right care but were understanding about limited resources. They suggested ways that decision support could be personalised.

Participants illustrated two stages of a journey after genetic testing sometimes identifying a *path_MMR* variant unexpectedly with a cancer diagnosis. Initial shock and overwhelming feelings were followed byadjustment and finding balance to live with Lynch, including dealing with uncertainty about future cancers. Once people understood choices and dealt with emotions, they could actively deliberate. Shared decision making was best navigated in partnership with educated, trusted healthcare professionals, but carriers sometimes found support lacking or difficult to access which necessitated finding information themselves.

Themes were mapped onto the levels at which they were operating, from taking individual control of health, through

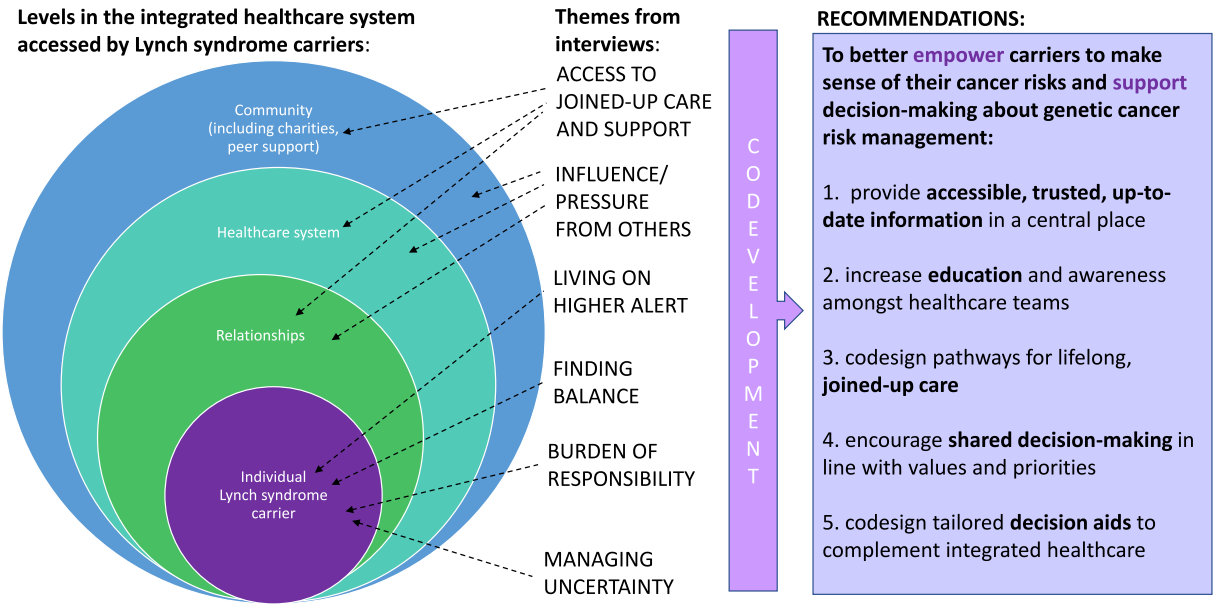

FIGURE 2 | Conceptual model displaying themes from qualitative interviews mapped onto the levels of integrated healthcare at which they were operating. Analysis suggested gaps in current practice related to information provision, joined-up care pathways and decision support for Lynch syndrome carriers. Recommendations are presented for codevelopment of better empowerment and support for carriers to make sense of their genetic cancer risks and make decisions about risk management options that are time-sensitive and in line with their values and priorities.

relationships with healthcare professionals, loved ones and community.

The themes identified the need to empower carriers to make sense of their personalised cancer risks and be supported to make decisions about genetic cancer risk management through.

1. Accessible, trusted, up-to-date information in a central place,
2. Increased education and awareness amongst healthcare teams,
3. Codesigned pathways for lifelong, joined-up care,
4. Encouraging shared decision-making in line with values and priorities,
5. Codesigned, tailored decision aids to complement integrated healthcare.

Recommendations were constructed based on lived experiences and the researcher's interpretation of how these should inform improved care, showcasing the value of codesign to increase acceptability, usefulness and relevance [30].

Recommendations

1. Information

Carriers described a range of coping strategies when learning to live with Lynch, including self-reliance. They proactively sifted through online information, peer groups and charities. More personalised information and signposting to trusted resources after genetic testing was desired. Research in Ireland and North America has also suggested that carriers frequently encounter a lack of relevant information when they are diagnosed or making time-sensitive decisions [15, 31, 32].

2. Education

It was burdensome but accepted that participants sometimes needed to self-advocate to access the correct care. This involved educating others about Lynch, including healthcare professionals, which could damage trust. Interviews with General Practitioners (GPs) have reinforced the need for more GP education about daily aspirin to reduce cancer risk [33], however some suggested solutions like joining multidisciplinary team meetings with Genetics services would be logistically difficult to implement due to limited staff and time [34]. Educational initiatives have emerged to provide 'just in time' resources (see https://www.genomicseducation.hee.nhs.uk/genotes).

3. Joined-up care

Lynch confers organ-specific cancer risks that vary depending upon gene, age, gender and treatment. Participants wanted personalised, joined-up support. This required them to navigate levels of integrated healthcare and community, something they did not find easy or seamless.

Innovative services have been initiated with government funding for a register of *path_MMR* variant carriers in England [35], direct contact of relatives by genetics services in the Netherlands [36] and web-based platforms worldwide [14, 37–39]. Such approaches should be considered more routinely due to the number of people that have not been offered genetic testing or were not informed when a pathogenic variant was found in their family [35, 40]. Integrated working between healthcare teams would make care more joined-up and holistic including access to psychosocial care, something not always experienced by carriers [5, 15].

4. Shared decision-making

Barriers to management guideline adherence such as trust, decision delay/avoidance or quality of life concerns should be elicited through discussion about values, priorities and preferences with healthcare professionals. Shared decision-making can lower decisional conflict, improve decision quality and possibly health outcomes [19, 41]. However, due to service limitations, carriers were often left to guide their own deliberation, using initiative, digital skills and contacts.

5. Decision support

UK-based participants described an overstretched NHS with regional variation. Suboptimal information to support carriers has also been described in other research [32]. More meaningful interventions include decision aids to complement genetic counselling [5, 39] and signposting to charities and peer groups [15]. Such interventions could reduce unmet needs and preserve clinic time for personalised genetic counselling [17, 42], to navigate feelings such as fear and guilt, which could otherwise cause people to become 'stuck' and avoid decision-making. The number of genetics professionals has not increased in line with demand, making complementary public-facing resources important.

Findings suggest a key goal in the NHS Long Term Plan could be achieved by empowering people to self-manage supported by digital tools [43, 44], crucial to realise the genomic medicine strategy to embed genomics across the NHS for improved health outcomes and precision medicine [45]. This study builds on recent research highlighting information needs for carriers [15, 31, 32] and extends this work by recommending codesign of a reliable information hub that is based on empirical evidence, relevant to the people using it and supports decision-making.

4.1 | Limitations

No *path_PMS2* variant carriers were recruited. More research is needed including carriers with lower cancer risks, which may affect experiences and decisions. Most participants identified as having white ancestry and were highly educated. It was not possible to analyse whether the sample who did not take part were demographically different. Underserved groups, such as those with lower literacy and some marginalised ethnicities (e.g., black African or Caribbean) were not captured, preventing exploration of specific barriers among these groups. Future research should compare the needs of people who recently had genetic testing, those who were tested many years ago, and others who might also find the decision aid online.

4.2 | Clinical Implications

Codesign of improvements to information, care and decision support throughout the lifespan and integrated care system could empower carriers to make decisions that are in line with their values and preferences.

5 | Conclusions

Findings from this qualitative study provided novel insight into the lived experiences of Lynch syndrome carriers including males and females with varied histories of cancer and at different stages of decision-making about genetic cancer risk management. Analysis of qualitative interview data indicated that Lynch syndrome carriers wanted personalised, trusted, up-to-date information to support shared decision making with educated healthcare professionals. They found joined-up care lacking when considering personalised, timely decisions. The proposed conceptual model for integrated care considers time- and context-specific priorities for the individual, their family and other relationships. This is likely to work best in partnership, with shared decision making as a 'method of care' [9] that challenges power imbalance and respects personal choice to make the right decision, at the right time.

Author Contributions

Conception and design of the manuscript: K.K.; involved in drafting the manuscript or revising it critically for intellectual content: K.K., K.M., L.T., R.F., D.E., C.F., E.K.B., H.H., K.S., K.H., M.J.E.; giving final approval of the manuscript: K.K., K.M., L.T., R.F., D.E., C.F., E.K.B., H. H., K.S., K.H., M.J.E., agreed to be accountable for all aspects of the work: K.K., K.M., L.T., R.F., D.E., C.F., E.K.B., H.H., K.S., K.H., M.J.E.

Acknowledgements

The researcher would like to thank all participants in the interview study who shared their experiences, Lynch Syndrome UK and Merrie Gowie, Research Practitioner at the South West Thames Centre for Genomics for assistance with recruitment and genomic counselling trainees Isabelle Rennocks, Eleanor Firth and Eleanor Summers for assistance with Table 1.

CanGene-CanVar Patient Reference Panel members: Caroline Dale, Sue Duncombe, Rochelle Gold, Sonia Patton, Warren Rook, Richard Stephens, Lesley Turner (Chair), Frankie Vale, Helen White, Ivan Woodward, Steve Worrall, Julie Young.

International Lynch Decision Aid Stakeholder Panel members: Munaza Ahmed, Lyndsy Ambler, Antonis Antoniou, Stephanie Archer, Ruth Armstrong, Elizabeth Bancroft, Kristine Barlow-Stewart, Lily Barnett, Marion Bartlett, Julian Barwell, Dany Bell, Cheryl Berlin, Felicity Blair, Matilda Bradford, John Burn, Sarah Cable, Melissa Cambell-Kelly, Dharmisha Chauhan, Ruth Cleaver, Beth Coad, Gaya Connolly, Gillian Crawford, Emma Crosbie, Victoria Cuthill, Tabib Dabir, Mev Dominguez Valentin, Eleanor Davies, Glyn Elwyn, Mary Jane Esplen, D. Gareth Evans, Pia Fabricius, Andrea Forman, Kaisa Fritzell, Claire Giffney, Joana Gomes, Rebecca Hall, Helen Hanson, Menna Hawkins, Deborah Holliday, Roberta Horgan, Karen Hurley, Margaret James, Ros Jewell, Siobhan John, Victoria Kiesel, Anna Koziel, Anjana Kulkarni, Fiona Lalloo, Helen Liggett, Aela Limbu, Kate Lippiett, Anne Lowry, Manami Matsukawa, Ranjit Manchanda, Tracie Miles, Shakira Milton, Pål Møller, Kevin Monahan, Laura Monje-Garcia, Gabriela Moslein, Alex Murray, Jennie Murray, Kai-Ren Ong, Christine Patch, Anbu Paramasivam, Alison Pope, Sarah Pugh, Imran Rafi, Gabriel Recchia, Nicola Reents, Neil Ryan, Sibel Saya, Raza Sayyed, Salma Shickh, Toni Seppala, Lucy Side, Katie Snape, Sian Smith, Tracy Smith, Barbara Stayner, Eriko Takamine, Katrina Tatton-Brown, Helle Vendel Petersen, Robert Volk, Karen Westaway, Nikki Warner, Jennifer Wiggins, Lisa Wilde, Jennet Williams, Catherine Willis, Elizabeth Winchester, Emma Woodward, Alice Youngs.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.