App Evaluation

To help shape future care for Lynch Syndrome Carriers

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So far we have had 106 Lynch Syndrome Carriers take part, answering questions on…

1

Experiences and challenges as a Lynch Syndrome Carrier

2

How or if you use technology to help your health or wellbeing

3

Potential features for an app that helps Lynch Syndrome Carriers

4

Interest in an app to support Lynch Syndrome Carriers

5

Any concerns you may or may not have toward app usage?

6

Your view on what else could be done to support carriers

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Sample and method

Our survey was sent out to Lynch Syndrome Carriers in the UK to take part in to let us know the challenges they face and their response to an app to support them.

10 minute quantitative online survey, made up of both closed and open ended questions.

Please see notes on each slide for exact question wording.

The data in this PowerPoint is a sample of n=106 Lynch Syndrome Carriers who were invited to take part by Prof Julian Barwell, clinical geneticist at University of Leicester and by Lynch Syndrome UK

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A variety of challenges of living as a Lynch Syndrome Carrier have already been identified, including…

Having a Lynch syndrome specialist doctor to turn to if needed (73%)

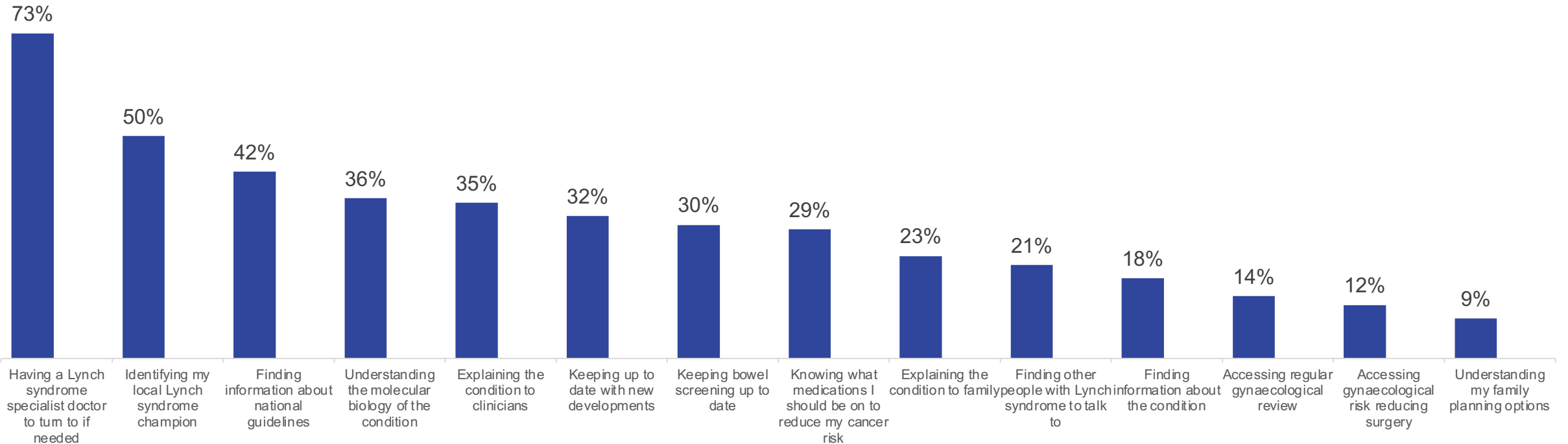Identifying my local Lynch syndrome champion (50%)

Finding information about national guidelines (42%)

Top 3 challenges reported so far. Based on those answering 6 or 7 on a 1-7 scale, where 7 is a classed as a serious challenge. Base, n=106. Lynch Syndrome Carriers UK

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Lynch Syndrome Carriers have a range of challenges to navigate

Challenges in Lynch Syndrome Management in descending order

Challenge	%
Having a Lynch syndrome specialist doctor to turn to if needed	73%
Identifying my local Lynch syndrome champion	50%
Finding information about national guidelines	42%
Understanding the molecular biology of the condition	36%
Explaining the condition to clinicians	35%
Keeping up to date with new developments	32%
Keeping bowel screening up to date	30%
Knowing what medications I should be on to reduce my cancer risk	29%
Explaining the condition to family	23%
Finding other people with Lynch syndrome to talk to	21%
Finding information about the condition	18%
Accessing regular gynaecological review	14%
Accessing gynaecological risk reducing surgery	12%
Understanding my family planning options	9%

Based on those answering 6 or 7 on a 1-7 scale, where 7 is a classed as a serious challenge. Base, n=106. Lynch Syndrome Carriers UK

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Lynch Syndrome Carriers who we've spoken to so far are least satisfied with their access to information and support vs others aspects

Top 3 areas of dissatisfaction – answering 1-3 on a 7-point scale

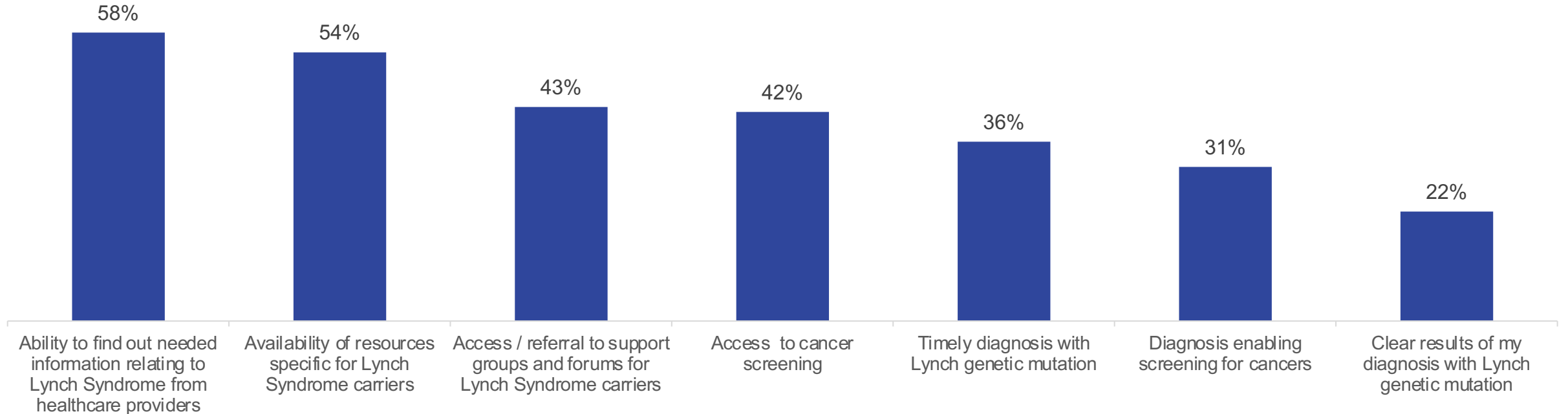Ability to find out needed information relating to Lynch Syndrome from healthcare providers – 58%

Availability of resources specific for Lynch Syndrome carriers – 54%

Access / referral to support groups and forums for Lynch Syndrome carriers – 43%

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Lynch Syndrome Carriers have a range of challenges to navigate

Dissatisfaction with aspects of Lynch Syndrome Management

58%	54%	43%	42%	36%	31%	22%
Ability to find out needed information relating to Lynch Syndrome from healthcare providers	Availability of resources specific for Lynch Syndrome carriers	Access / referral to support groups and forums for Lynch Syndrome carriers	Access to cancer screening	Timely diagnosis with Lynch genetic mutation	Diagnosis enabling screening for cancers	Clear results of my diagnosis with Lynch genetic mutation

Based on those answering 1, 2, 3 on a 1-7 scale.

Base, n=106. Lynch Syndrome Carriers UK

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Lynch Syndrome diagnosis is an area of comparative satisfaction for carriers

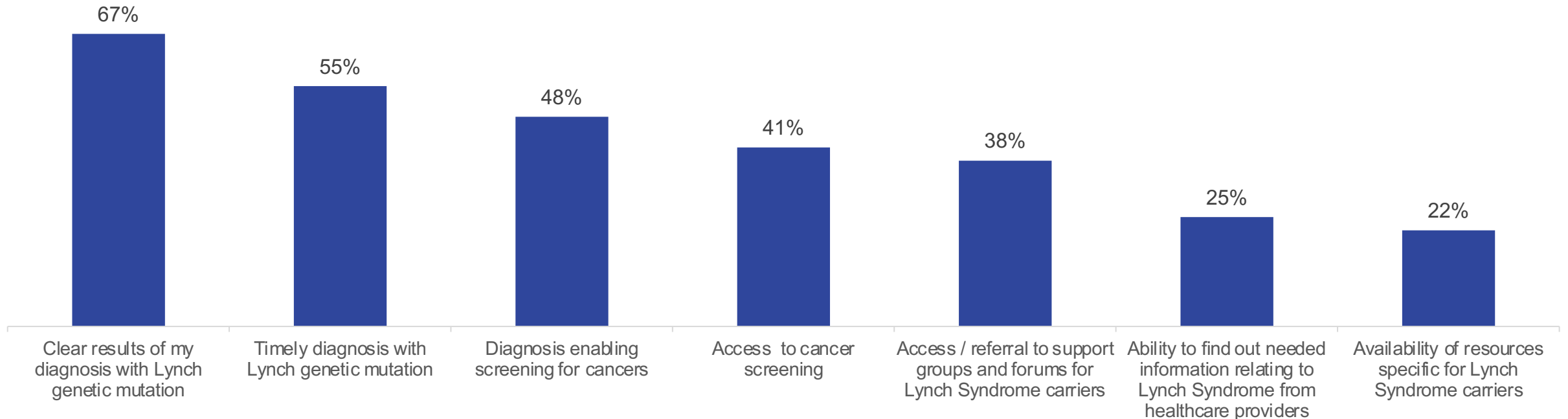## Top 3 areas of satisfaction – scoring 5, 6, 7 on 7-point scale

Clear results of my diagnosis with Lynch genetic mutation – 67%

Timely diagnosis with Lynch genetic mutation – 55%

Diagnosis enabling screening for cancers – 48%

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Lynch Syndrome diagnosis is an area of comparative satisfaction for carriers

Satisfaction with aspects of Lynch Syndrome Management

Aspect	Percentage
Clear results of my diagnosis with Lynch genetic mutation	67%
Timely diagnosis with Lynch genetic mutation	55%
Diagnosis enabling screening for cancers	48%
Access to cancer screening	41%
Access / referral to support groups and forums for Lynch Syndrome carriers	38%
Ability to find out needed information relating to Lynch Syndrome from healthcare providers	25%
Availability of resources specific for Lynch Syndrome carriers	22%

Based on those answering 5, 6 or 7 on a 1-7 scale.

Base, n=106. Lynch Syndrome Carriers UK

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There are high comfort levels of app usage already

Comfort with apps

92%

State they are comfortable using apps.

With 79% of the total sample stating they are completely comfortable and familiar with the use of apps

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The vast majority of Lynch Syndrome Carriers we surveyed use apps for their health in some way

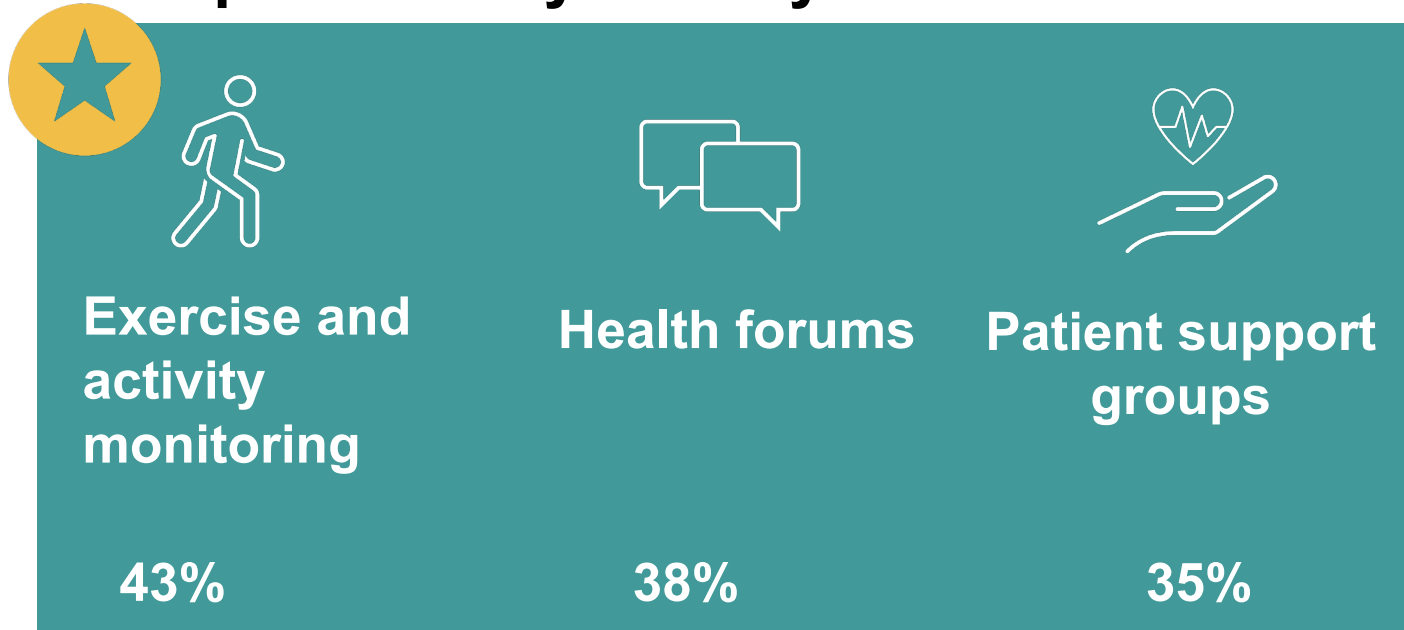*Only 3% report not using health apps at all.*

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Carriers use apps for a range of health reasons, fairly regularly

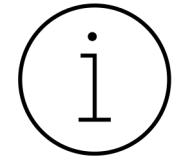## Frequency of usage of health apps
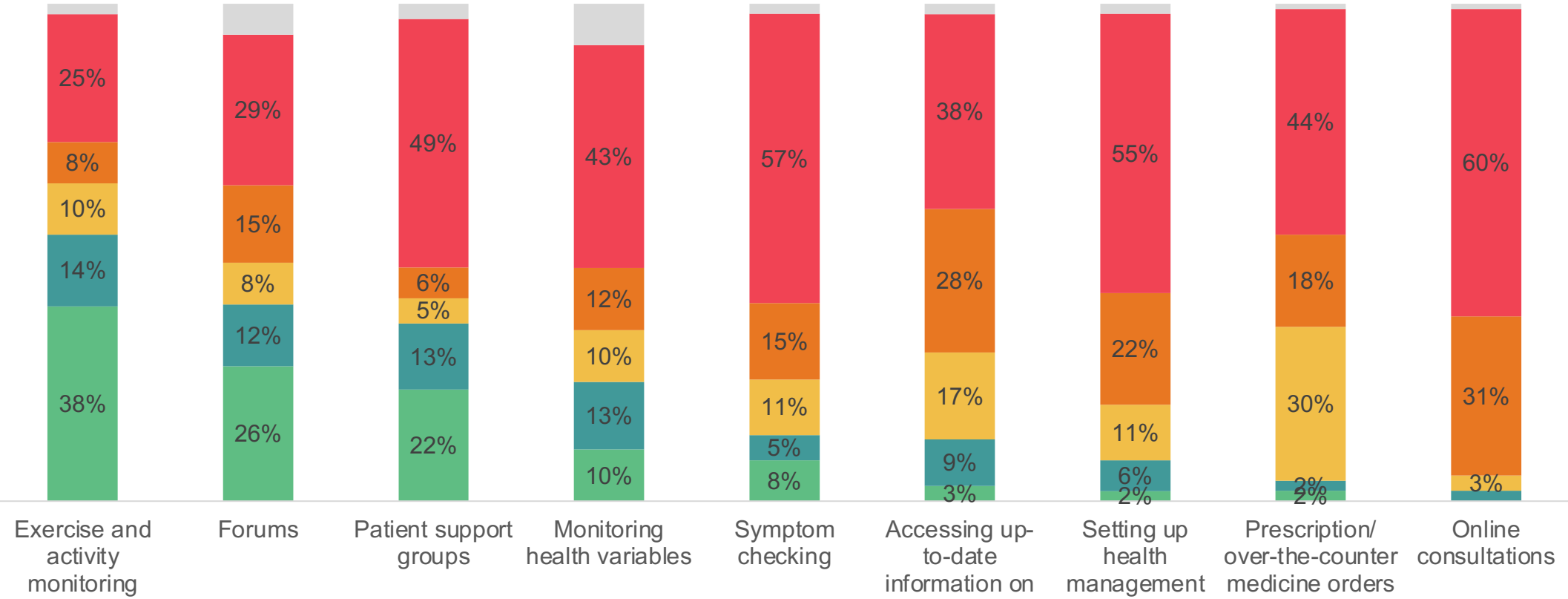
Top uses daily/ weekly

Used more monthly

Exercise and activity monitoring

Health forums

Patient support groups

Prescriptions

Accessing information on treatment

43%

38%

35%

34%

29%

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~50% of Lynch Syndrome Carriers use health apps to access forums and support groups at least weekly

Detailed breakdown of app usage will go here

Legend: ■ Daily ■ Weekly ■ Monthly ■ Less than monthly ■ Never ■ Don't know

Category	Daily	Weekly	Monthly	Less than monthly	Never
Exercise and activity monitoring	38%	14%	10%	8%	25%
Forums	26%	12%	8%	15%	29%
Patient support groups	22%	13%	5%	6%	49%
Monitoring health variables	10%	13%	10%	12%	43%
Symptom checking	8%	5%	11%	15%	57%
Accessing up-to-date information on healthcare and treatment	3%	9%	17%	28%	38%
Setting up health management related reminders	2%	6%	11%	22%	55%
Prescription/over-the-counter medicine orders	2%	2%	30%	18%	44%
Online consultations	3%			31%	60%

Top reasons for ever using health apps (majority)

- Exercise
- Accessing up to date info on healthcare and treatment
- Forums
- Ordering medication
- Monitoring health variables
- Patient support groups

Base, n=106. Lynch Syndrome Carriers UK

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Potential uptake of an app is high

95%

stated that given the listed features they would be likely to use such an app if it were developed

Base, n=106. Lynch Syndrome Carriers UK

Carriers are excited by what the app might have in store

"Excellent project. Please keep Lynch Syndrome Ireland in the frame"

"Very useful for myself, my family and my healthcare team"

"Anything to help manage this Syndrome and stay up to date is lifesaving. **Knowledge is power.** I am on a clinical trial which has improved my lot considerably but it only came to be because I had access to Lynch Syndrome UK on Facebook and a clued up previous consultant."

"Sounds a brilliant idea. Everything in one place. Thank you!"

"I think this would be so helpful"

Verbatim provided in open text answers by Lynch Syndrome Carriers surveyed. Base n=106

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Patients are keen to be involved in the apps development

81% would like to be involved in some way on the development of such an app

Answered 'Yes' or 'No, but please keep me up to date with developments'

40% would like to be take part in focus groups to help the development of the app
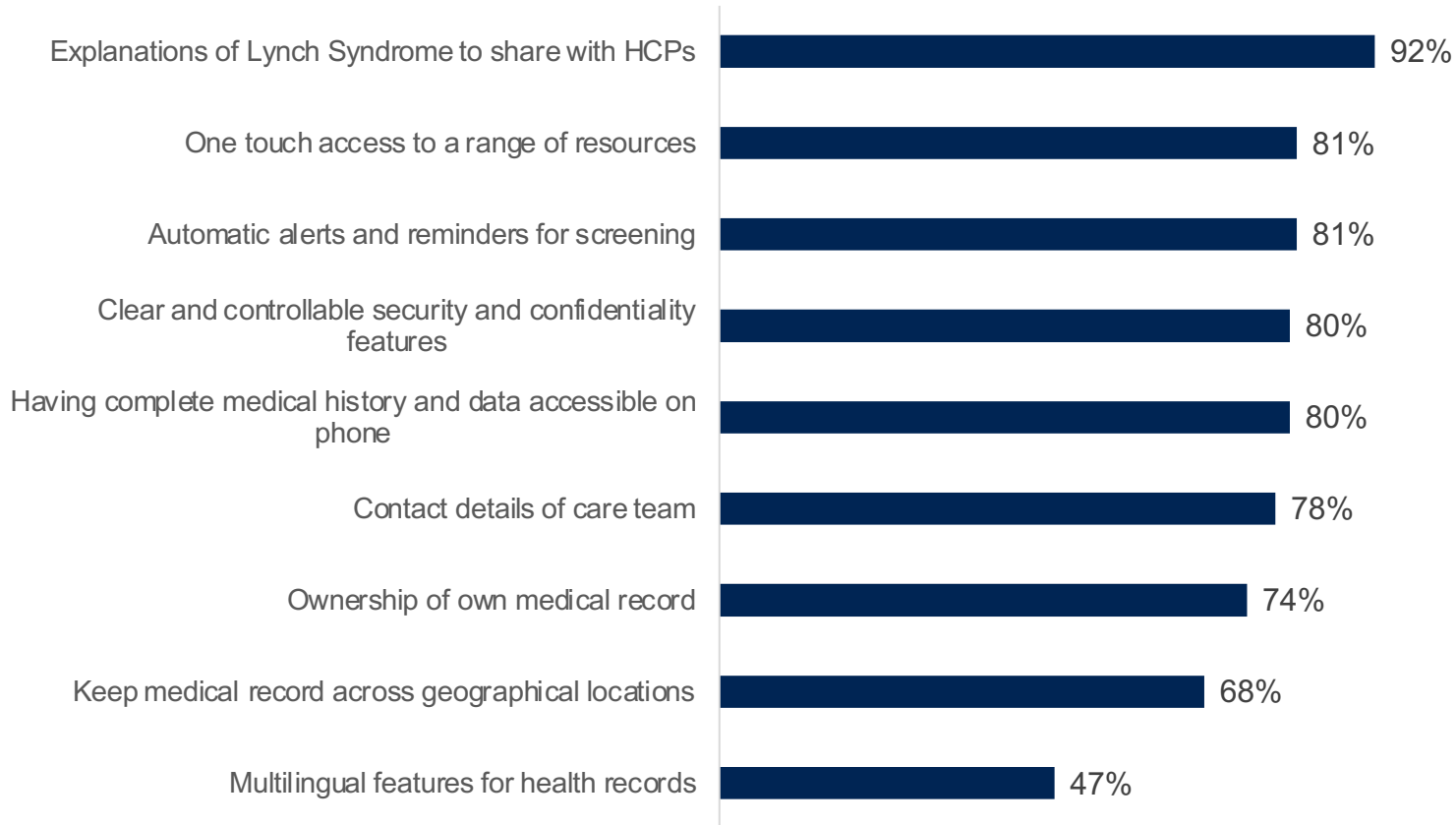
Answered 'Yes'

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All listed functions of the app are of high interest to our respondents

Function	Percentage
A suggested list of screening checks I can show to my GP to reduce my cancer risk	96%
Guidance behind the red flag symptoms which would warrant further testing and/or treatment	94%
Updates about research and recommended management of Lynch Syndrome	92%
Knowing who my Lynch Syndrome regional champion is	89%
An overview of national guidelines	86%
Basic explanation of Lynch Syndrome for my clinicians	86%
A surveillance diary to make sure that I am up to date	82%
Reminders and alerts for screening appointments	82%
A way of communicating digitally and securely with my GP/ clinical team	82%
Digital annual health check reviews	81%

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Respondents are most interested in an easy-to-use app to guide communication

Explanations of Lynch Syndrome to share with HCPs — 92%

One touch access to a range of resources — 81%

Automatic alerts and reminders for screening — 81%

Clear and controllable security and confidentiality features — 80%

Having complete medical history and data accessible on phone — 80%

Contact details of care team — 78%

Ownership of own medical record — 74%

Keep medical record across geographical locations — 68%

Multilingual features for health records — 47%

> Link to child health records so I can manage my child's risk of inheriting lynch syndrome

> I think that information should be clear and not complicated for people who have just found out they have Lynch Syndrome as a lot of the information just goes over your head, as your like a rabbit in the headlights, being scared, frightened and of course once you have been told it's a cancer gene puts the fear of god into people.

> A page for information easily shareable on different formats (WhatsApp, Messenger) for the particular mutation and contacts & procedure to get tested.

> *List of organisations who can help to support LS carriers. Having a place for knowledge and support is crucial to a patient and knowing they are not alone*

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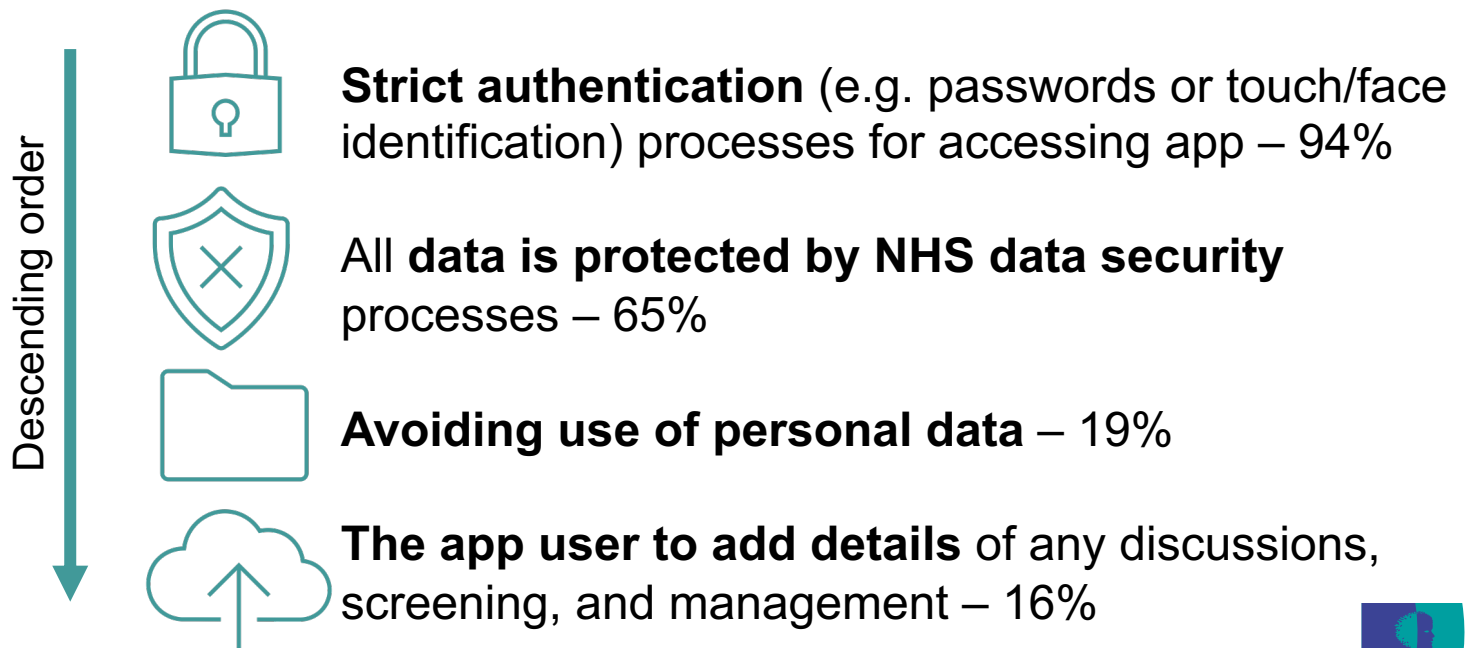# Data privacy concerns top the list for potential barriers, however only for 1 in 3
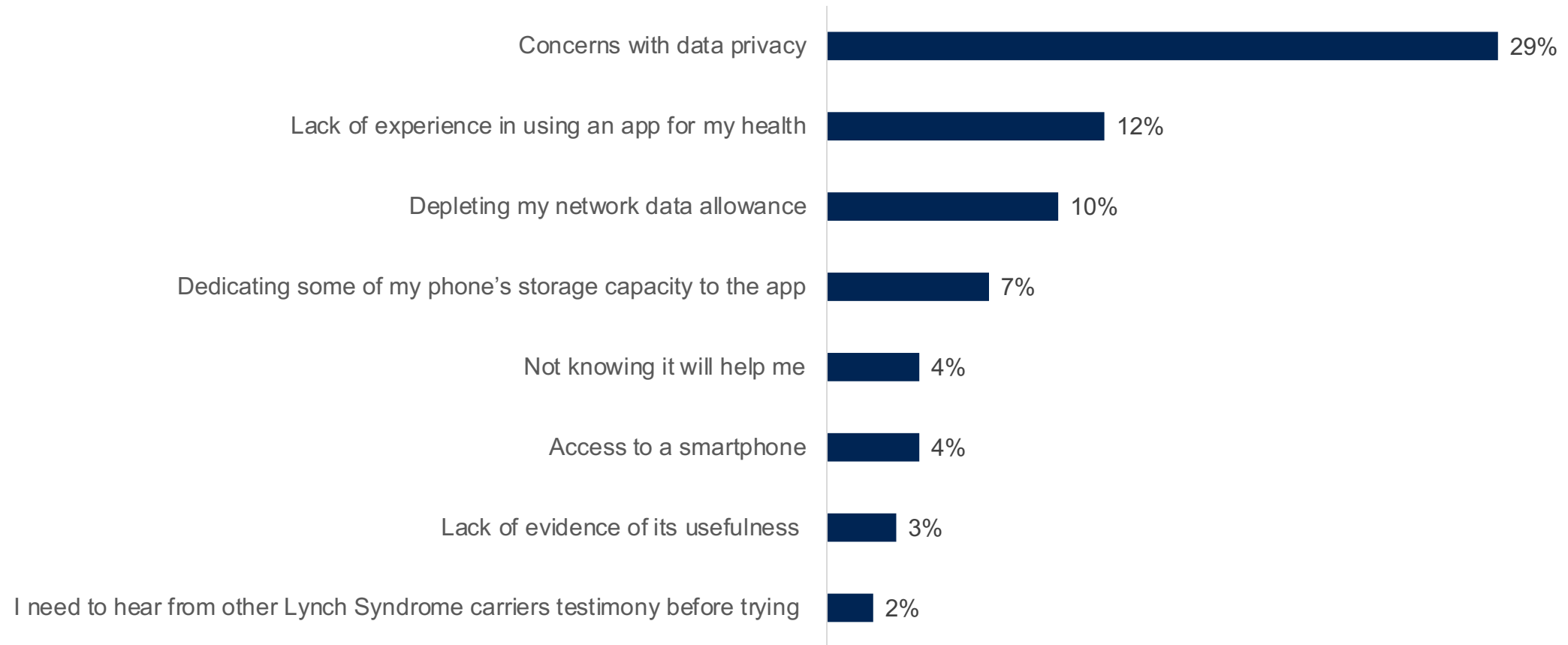
Concerns with data privacy	29%
Lack of experience in using an app for my health	12%
Depleting my network data allowance	10%
Dedicating some of my phone's storage capacity to the app	7%
Not knowing it will help me	4%
Access to a smartphone	4%
Lack of evidence of its usefulness	3%
I need to hear from other Lynch Syndrome carriers testimony before trying	2%

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Privacy concerns can be reduced by strict authentication and NHS data security processes

Ways to reassure on privacy concerns

Descending order

Strict authentication (e.g. passwords or touch/face identification) processes for accessing app – 94%

All **data is protected by NHS data security** processes – 65%

Avoiding use of personal data – 19%

The app user to add details of any discussions, screening, and management – 16%

Base, n=31. Lynch Syndrome Carriers UK concerns over app data privacy

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79% would consent to using their app data
The remainder simply would like more information

Thank you

Reena Sangar   Jemma Reast   Byron Ritson

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Ipsos MORI's standards & accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Moreover, our focus on quality and continuous improvement means we have embedded a 'right first time' approach throughout our organisation.

ISO 20252 – is the international market research specific standard that supersedes BS 7911 / MRQSA & incorporates IQCS (Interviewer Quality Control Scheme); it covers the 5 stages of a Market Research project. Ipsos MORI was the first company in the world to gain this accreditation.

MRS Company Partnership – By being an MRS Company Partner, Ipsos MORI endorse and support the core MRS brand values of professionalism, research excellence and business effectiveness, and commit to comply with the MRS Code of Conduct throughout the organisation & we were the first company to sign our organisation up to the requirements & self regulation of the MRS Code; more than 350 companies have followed our lead.

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This work was carried out in accordance with the requirements of the international quality standard for market research, ISO 20252

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