

The Next Generation: The Experience of Parents with Lynch Syndrome

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Introduction

- If one parent carries a genetic mutation for Lynch syndrome, there is a 50% chance that it will be inherited by each child
- It is not surprising then, that parents are concerned for the well-being of their children
- In fact, the main reason parents undergo genetic testing is to obtain cancer risk information for their children
- Despite this, we know quite little about the experience of being a parent with Lynch syndrome

Project Overview

Study 1

- Questionnaires mailed to members of FGICR
- Asked about medical and family history, a variety of psychological variables, and other descriptive information
- Completed by 207 patients

Study 2

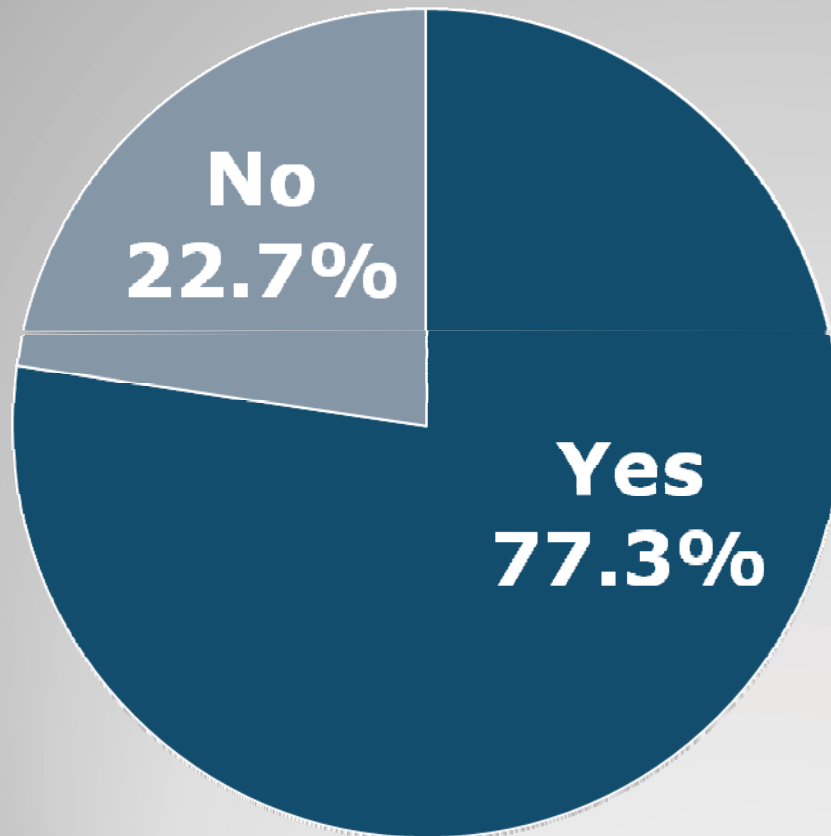
- Telephone interviews conducted with 22 Study 1 participants who are parents
- Asked a variety of questions about the experience of being a parent with Lynch syndrome

A snapshot of information from the questionnaire



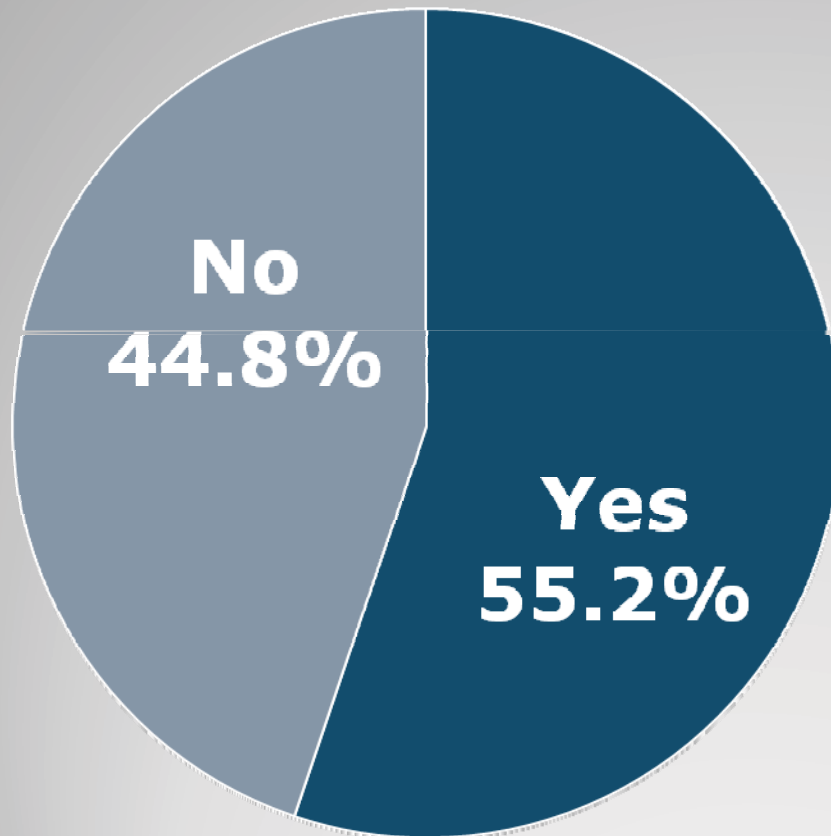
Study 1

Do you have biological children?



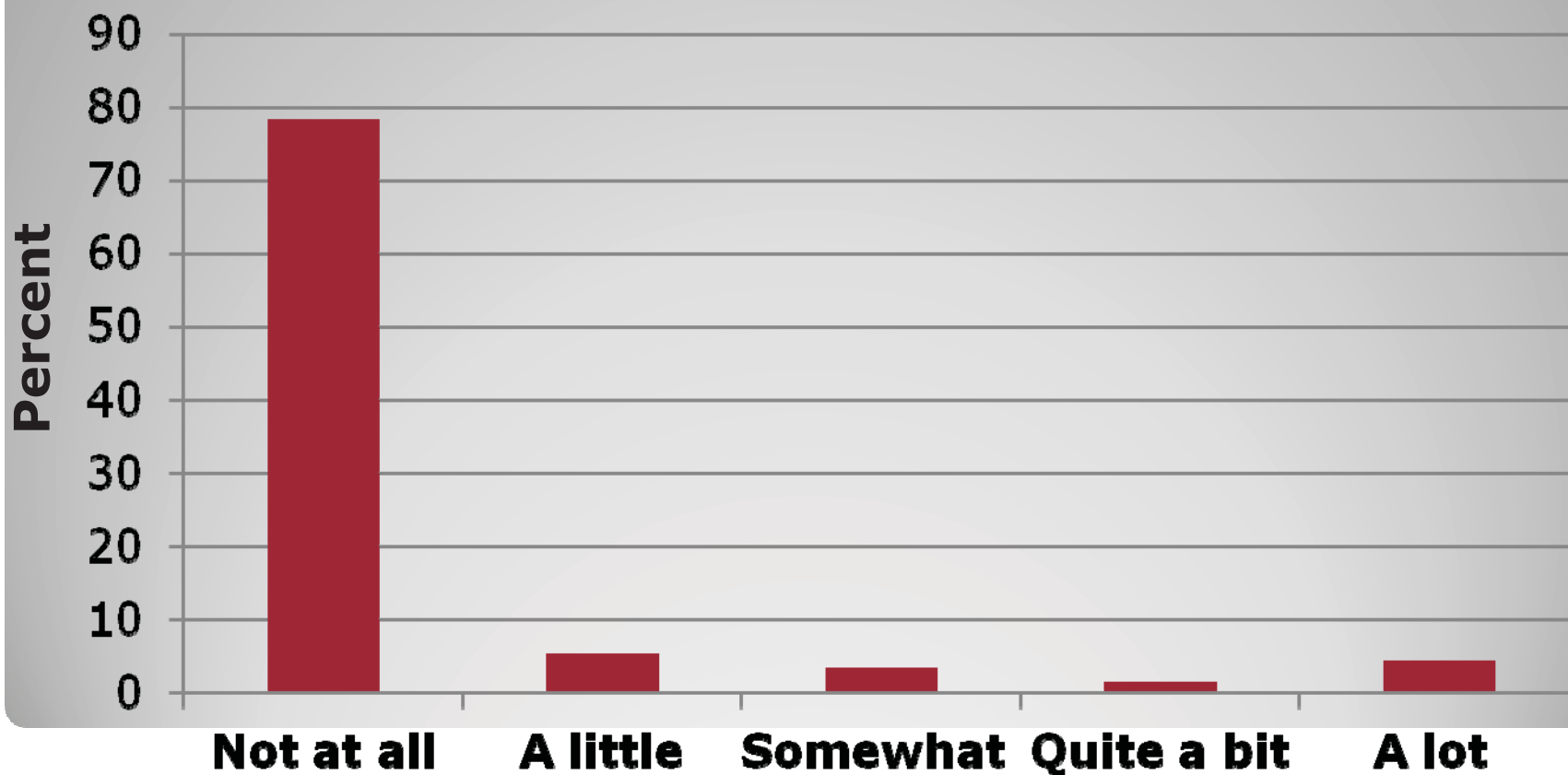
- Average 2.2 children
- 30.6% under age 18

Have your children (>18 years) been tested for Lynch syndrome?

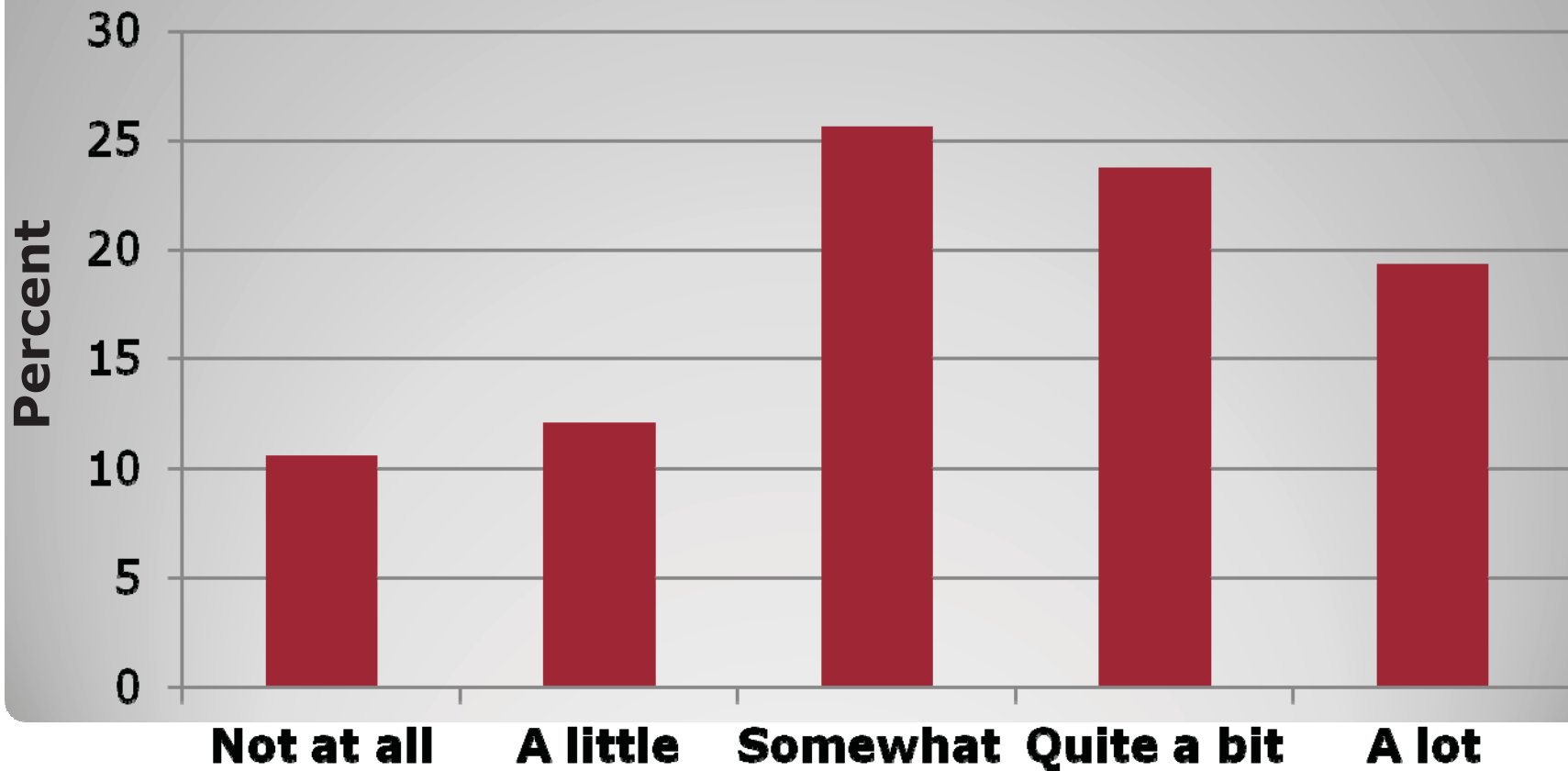


Of those tested, 56.9% have Lynch syndrome

Did cancer risk affect your decision to have children?



How much do you worry about your children's/grandchildren's chances of developing cancer?



Talking to Parents With Lynch Syndrome

Study 2



What are parents worried about?

Passing on the Gene to Children

- Children having to undergo future cancer screening procedures
- Fears of children developing cancer

Having Children Tested

- Psychological well-being of children
- Children's ability to obtain insurance in the future

Personal Health and Parenting

- Ability to care for children if diagnosed with cancer
- Financial concerns (e.g., employment)
- Fears about abandoning children

What helps parents to cope?

Openly talking about Lynch syndrome

Becoming knowledgeable about Lynch syndrome

Regularly undergoing cancer screening procedures

Living a healthier lifestyle (e.g., diet, exercise)

Engaging in spiritual practices

Talking to supportive individuals (e.g., friends, therapist)

How do parents react to having their children tested for Lynch syndrome?

If child is a gene carrier:

- Initial reactions of guilt, sadness, anger, anxiety

If child is not a gene carrier:

- Immediate relief

Regardless of carrier status:

- Increased feeling of control over the situation

Regardless of the test results, nearly all parents said they were happy their children were tested and stated they did not have any regrets

Talking to Children About Lynch Syndrome



Helpful Tips and
Strategies to Use at
Home

Should parents talk to kids about Lynch syndrome?



Parents' first instinct is often to protect their children by not discussing a diagnosis

However, research shows that children tend to cope better when the family is willing to talk about what is happening

The decision about when to talk to children comes down to parental judgment, but children are typically able to grasp concepts and cope well around **age 10**

Adapted from "A Beginner's Guide to BRCA1 and BRCA2"
The Royal Marsden NHS Foundation Trust (2013)

Tips for Talking to Kids about Lynch Syndrome

Use age appropriate language

Provide the name "Lynch syndrome" and explain the basics of what it is

Reassure them that having Lynch syndrome does not always result in cancer

Place a positive emphasis on the importance of knowing about Lynch syndrome (e.g., improved screening)

Prompt children to ask questions

Remember that talking about Lynch syndrome is an ongoing discussion

A special thank you to all of the members of the FGICR who participated in this research!

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