

# Freedom of Information Request – FH NICE Guidance

HEART UK

# Contents

- Background
- Methods
- Results

# Background

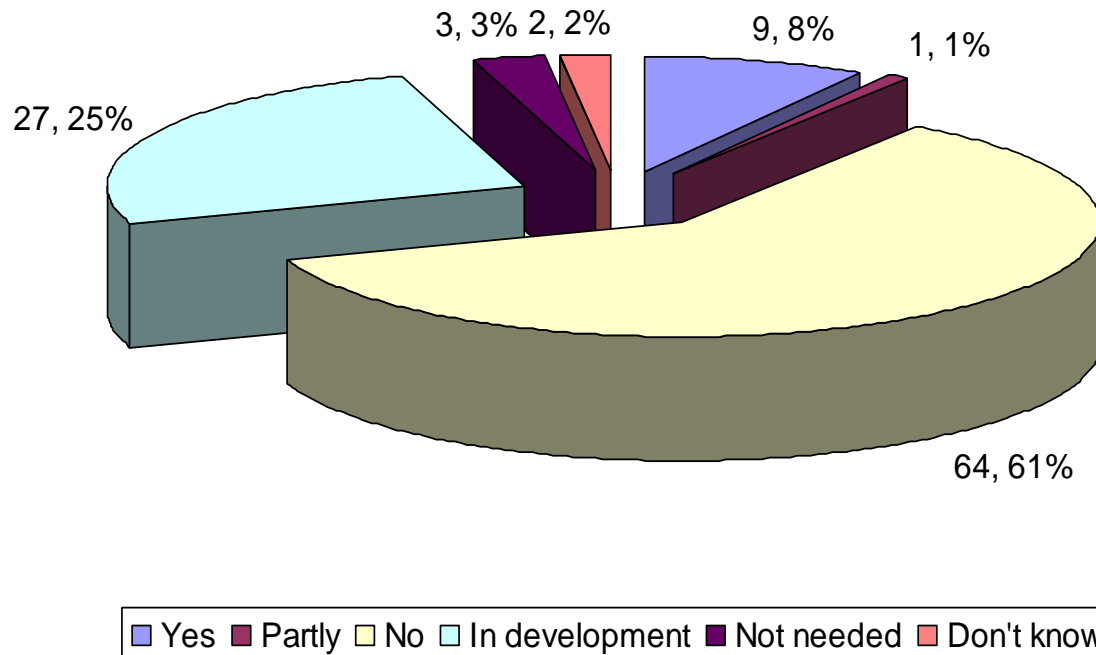
- The estimated prevalence of FH is 1 in 500, suggesting 120,000 individuals are affected in the UK. FH is hugely under-diagnosed – a 2008 survey of lipid clinics indicates that only 15,000 cases are known at most.
- The purpose of this project was to build an accurate picture of the nature of services that have been commissioned in the 18 months since the guidance was issued in August 2008 to determine where services need to be improved around the country.

# Methods

- 152 surveys with a covering letter were posted to PCTs in England from HEART UK – January 2010
- 106 completed surveys were completed and analysed – May 2010
- 69% response rate

# Q1 - Any written plans?

Do you have written plans to support NICE Guidance on FH?

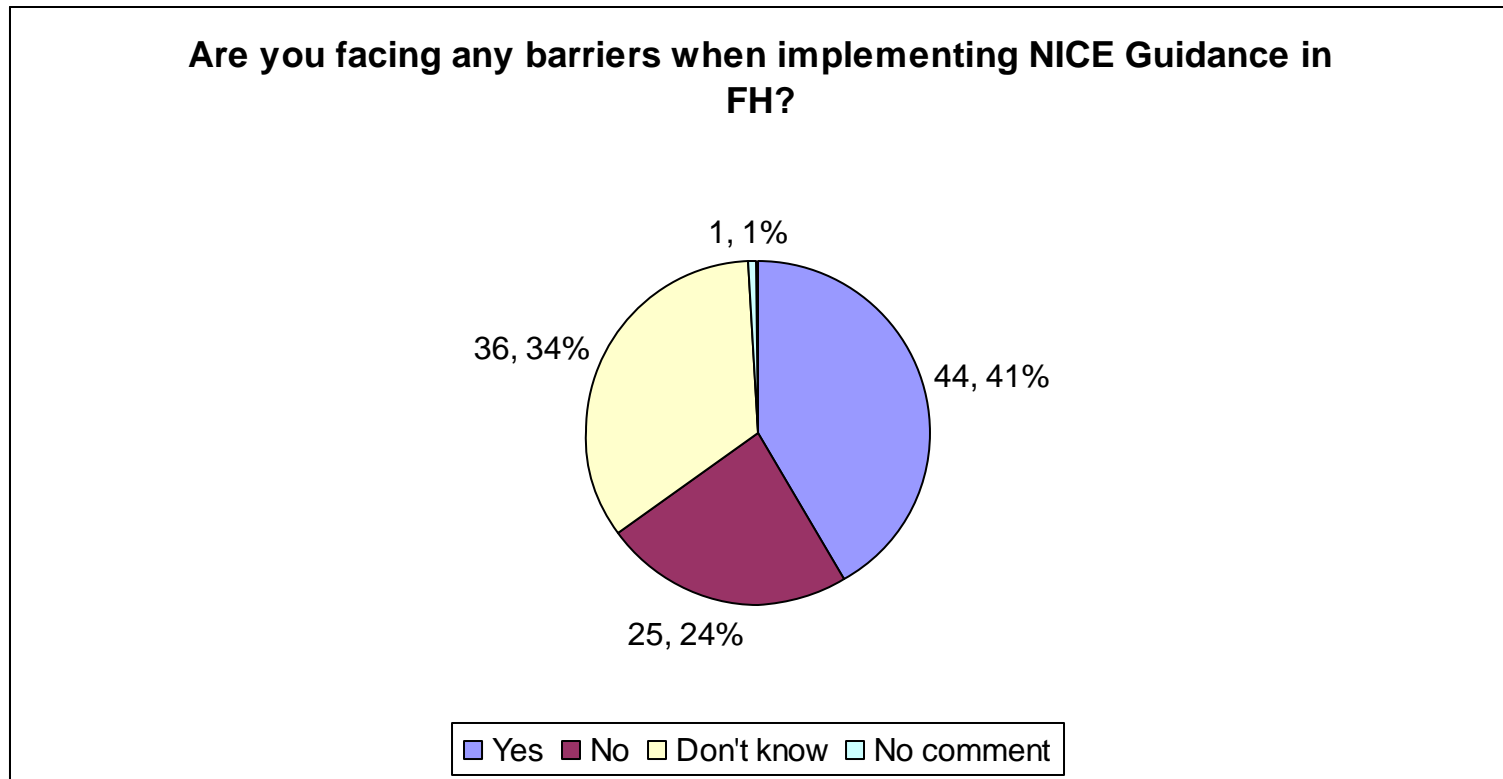


•64.61% said they did not have plans in place

# Q1a - supply these plans?

- Only 5.66% of respondents supplied plans for their implementation of the recent NICE guidance in Familial Hypercholesterolaemia (FH)
- 41.51% stated there were barriers preventing the implementation of this Guidance (CG71)

# Q2 – Barriers?



***44 (41%) PCTs are facing barriers when trying to offer a service to FH patients***

# Q3 – Lipid clinics

<b>Please list the lipid clinics in your area that you refer adult FH patients to</b>	<b>Count</b>	<b>%</b>
Yes - list is provided	49	46.23%
<b><i>No - there are none</i></b>	<b><i>30</i></b>	<b><i>28.30%</i></b>
Don't know	27	25.47%
<b>TOTAL</b>	<b>106</b>	<b>100.00%</b>

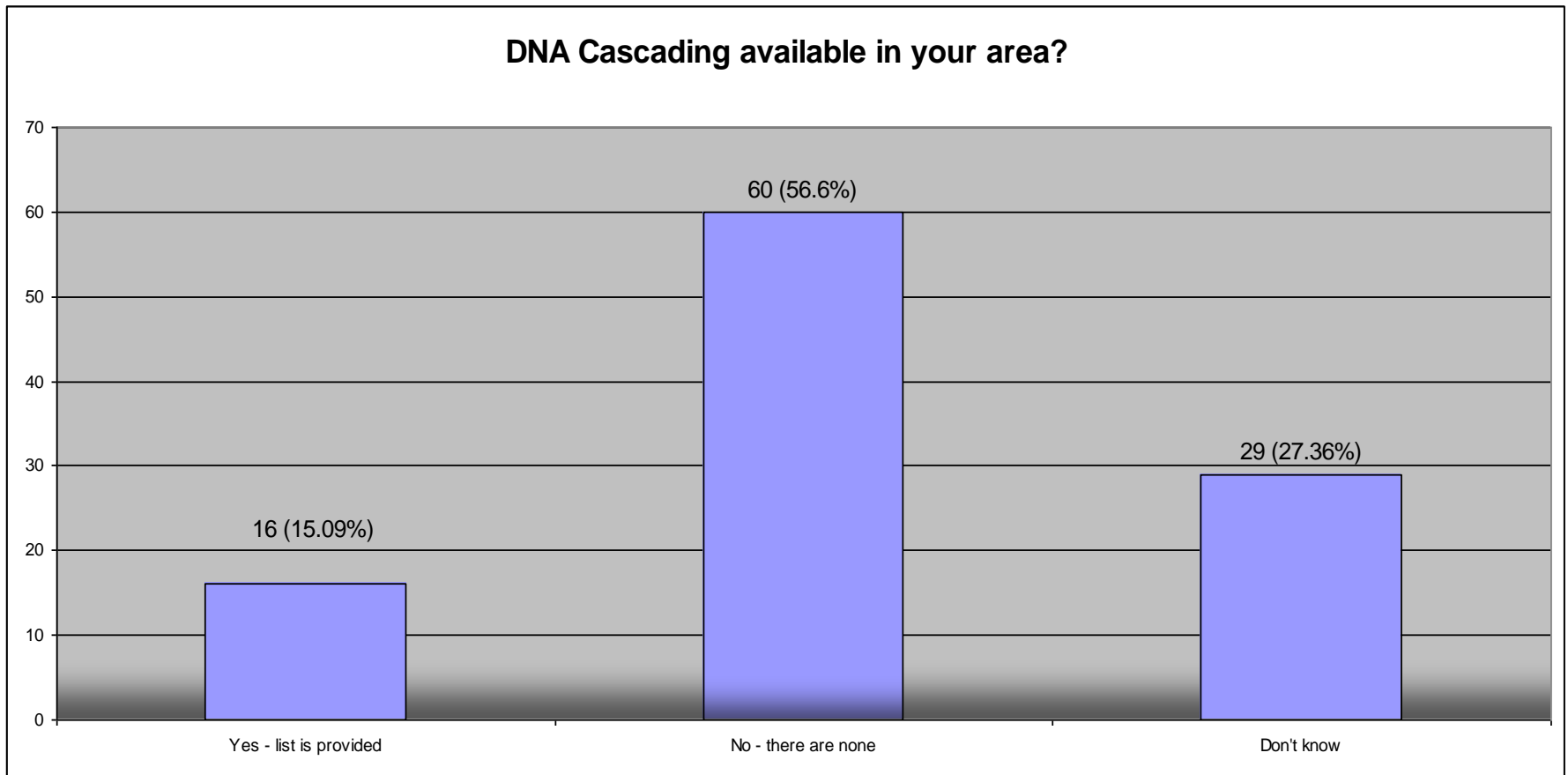


## Q3 - Lipid clinics

- 28.3% of PCTs stated there were no lipid clinics in their area that they can refer adult FH patients to
- 25.47% stated they didn't know the answer to this question

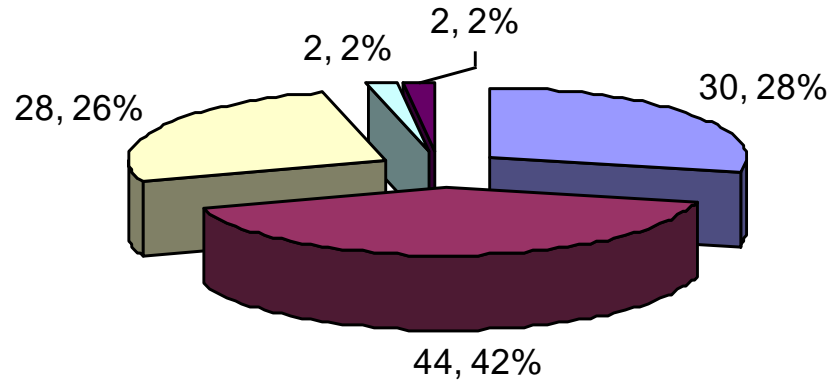
# Q4 – DNA Cascade testing

Please list the lipid clinics in your area that are able to carry out DNA cascade testing in adult FH patients?



# Q5 – Children with FH

Ability to list lipid clinics that offer services to children with FH



■ Yes - list is provided ■ No - there are none ■ Don't know ■ No comment ■ In development

***42% of PCTs do not have any provision of services for children with FH***

## Q6 & Q7

- Only 13 (12.26%) of PCTS are able to offer DNA cascade testing for children with FH in their area
- Only 9 (8.49%) of PCTS are able to provide plans for shared care arrangements for people with FH

# Q8 – Pregnant women

**Details of shared care arrangements for the care of pregnant women with FH**

