

Community views on the communication of Familial Hypercholesterolaemia genetic information within families

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Introduction

Cascade screening involves communicating health information about an individual to their relatives to inform them about a shared familial risk.

Relatives can either be informed directly through health professionals, or indirectly through their family member.

Direct contact has advantages, such as reducing the burden on individuals and improving recruitment into screening.

However, this method raises questions around responsibility for information provision, privacy and acceptability.

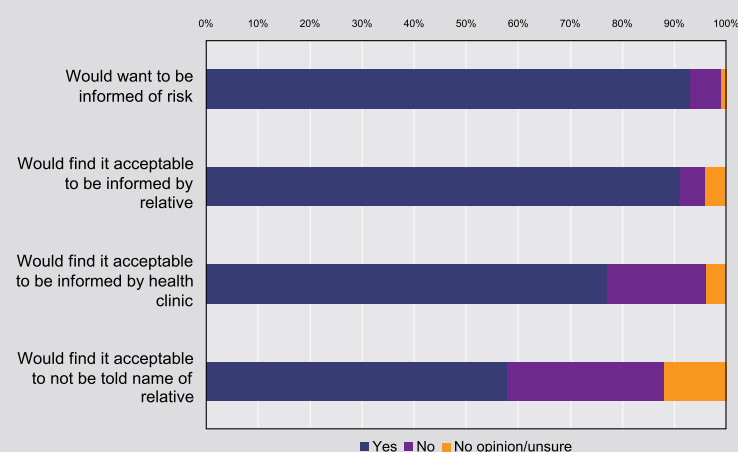
Objectives

To explore the views of the Western Australian community on cascade screening for Familial Hypercholesterolaemia (FH), focusing on:

- The desire of relatives to be informed about a familial risk.
- The acceptability of being informed by family and by health professionals.
- Preferences around how this information is shared.

Results

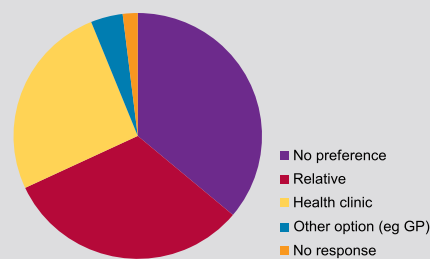
Acceptability of contact methods



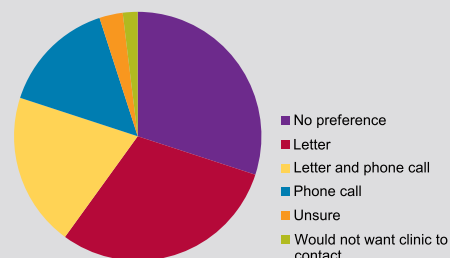
Methods

Cross sectional, Computer Assisted Telephone Interviewing survey. 430 respondents recruited randomly from the electronic version of the Western Australian telephone directory.

Preferences – Who provides the information



Preferences – How the health clinic provides information



Conclusions

Our findings suggest that for FH, a serious but treatable condition, the general community would want to know their familial risk and thus support the principle of 'the right to know'. In Australia a cascade screening policy of direct contact, while not necessarily preferred, would be supported by the majority of the community, as it appears to be in other countries.

It would be of value to determine why some find direct contact unacceptable. Providing the relative's name in correspondence from the cascade screening program could improve the acceptability of direct contact.