P20.06B

The use of an electronic health record to facilitate communication of additional findings in families.

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Introduction

- It is estimated that between 15-20% of relatives remain unaware of their potential risks from additional findings (1).
- The most common reasons for patients not informing relatives are: protecting themselves and their family against harm (i.e. against harmful information or feelings of guilt); family dynamics (i.e. estranged relatives); or a misunderstanding of the relevance of the information (2-6).
- The 100,000 Genomes Project – a project delivered by Genomics England to sequence 100,000 whole genomes from National Health Service patients with rare diseases and their families and patients with common cancers - offer to actively search for additional findings. This will likely make this situation more common as there may be no family history of disease, results may be hard to understand and explain and testing family members may become more important to try to determine clinical significance.
- The University Hospital Southampton NHS Foundation Trust have developed an electronic health record called My Medical Record (MyMR) which could be utilised as a way to improve communication of genetic information to at-risk relatives.

Aims

(i) to explore 100,000 Genome Project participants' views about communicating additional findings and (ii) to determine what proportion of 100,000 Genomes Project participants had used MyMR.

Method

All participants were recruited from the 100,000 Genomes Project. Participants were asked questions about their experiences of taking part in the project; the additional findings option; family communication; and their experience of using MyMR.

Results

MyMR is under used; over three quarters of participants have asked for additional findings; and almost 36% have not discussed having tests for additional findings with their families.

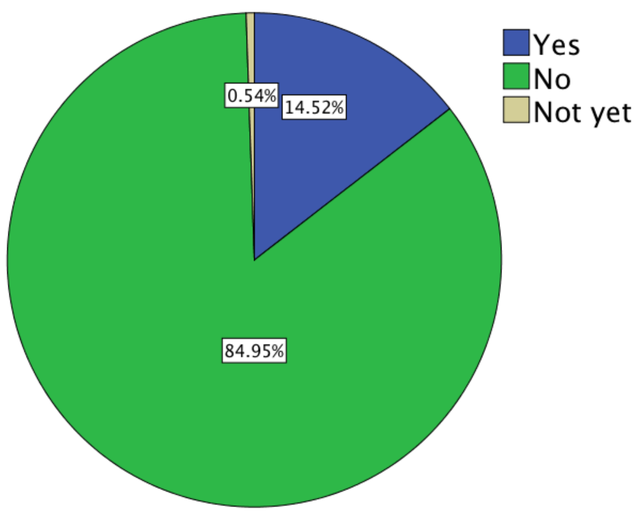

Figure 1. Have you used MyMR?

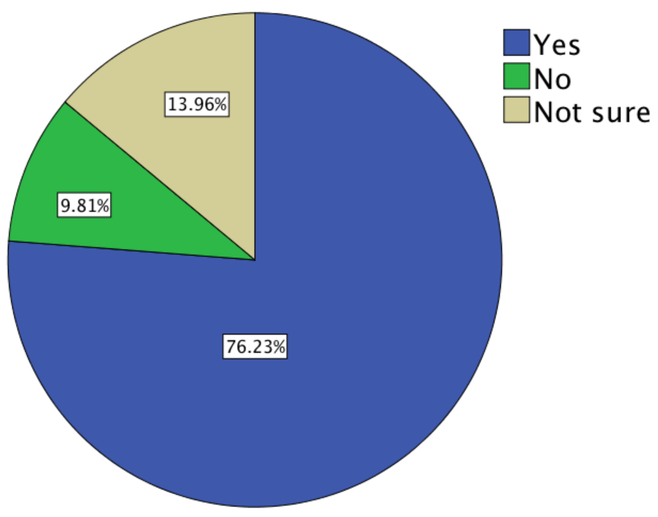

Figure 2. Did you decide to have additional tests?

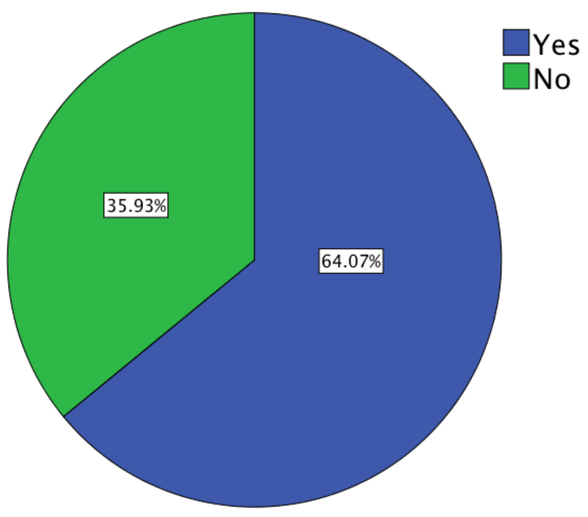

Figure 3. Have you told your family about additional test?

Positive about communicating genetic information

"I would, if it affected family members, then yes, I would definitely tell them, because information is a good thing. It would help them as well wouldn't it, it just wouldn't help just you, but it would help people related to you, so I think that would be a good thing to tell people and have that information so you can be aware of things." P50 (Parent of child with a rare disease)

Patients prefer to tell relatives themselves

"I would take that on quite happily and then obviously if they had problems or issues with it then they could go and see their doctor or something, to have it explained to them, but no, I'd be quite happy to pass that information on." P50 (Parent of child with a rare disease)

Passing on information diffuses responsibility

"It wouldn't worry me at all. I would give it to them. If they want to use that's fine, if they don't it doesn't really worry me. It's just that I've done my bit basically." P36 (Patient with a rare disease)

Interview as an intervention

"You've got me thinking now, maybe I should tell them." P34 (Parent of child with a rare disease)

Telling estranged relatives is challenging

"One of the brothers has been estranged for many years […] and so I said 'Well I'm going to write to him'. So, I spent ages writing this letter." P35 (Parent of child with a rare disease)

Conclusion

- MyMR and other web tools could be employed to overcome the issues highlighted by participants from the 100,000 Genomes Project when sharing genetic information with at-risk relatives.
- The interactivity of web-apps could mitigate some of patients' perceived barriers to communication by providing an efficient and focused view of the content to be communicated and by being more engaging and conducive to identifying and contacting relatives than (what is sometimes) a one-off clinical consultation.
- In the future we would like to explore: how to increase the use of MyMR and whether communication-based web-apps, such as Kintalk (that MyMR can integrate), could facilitate communication.

References: 1). Hodgson J, et al. Outcomes of a randomised controlled trial of a complex genetic counselling intervention to improve family communication. Eur J Hum Genet. 2016;24(3):356-60. 2). Wiens M, C, et al. Family genetic risk communication framework: guiding tool development in genetics health services. Journal of Community Genetics. 2013;4:233-42. 3). Chivers Seymour K, et al. What facilitates or impedes family communication following genetic testing for cancer risk? A systematic review and meta-synthesis of primary qualitative research. Journal of genetic counseling. 2010;19(4):330-42. 4). Palmquist AE, et al. "The cancer bond": exploring the formation of cancer risk perception in families with Lynch syndrome. Journal of genetic counseling. 2010;19(5):473-86. 5). Esplen MJ, et al. Development and validation of an instrument to measure the impact of genetic testing on self-concept in Lynch syndrome. Clin Genet. 2011;80(5):415-23. 6). Bleiker EM, et al. 100 years Lynch syndrome: what have we learned about psychosocial issues? Fam Cancer. 2013;12(2):325-39.

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