

Factors Affected Patient Decision to Participate in Genomic Research Projects

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Background

The most challenging step for researchers in clinical studies is patients recruitment. Many research studies did not complete the target sample size because there are not enough people willing to participate. The insufficient number of samples affects the timeline for the project and potentially skewed results. Low Patient recruitment and low retention is also one of the most challenges for sponsors because of financial losses. The aim of this study is to explore the reasons for participant's rejection, improve staff-patient communication and explore new tools to increase patient recruitment for laboratory based genomic research.

Objectives

- To determine factors that encourage patients to participate in genomic studies
- To Assess the level of challenges faced by the genetics investigators in recruitment of patients.
- To improve patients recruitment process in genetics research.

Methods

Online questionnaire was conducted among adult in Arabic language and was composed of following sections: personal information, knowledge about genetic research, Motivation, unwillingness and finally the type of information the patient wants to know before participation.

Results

In total 388 participants who completed all survey items, represented a response rate around 74.5%. The participants were predominantly female 70%. The mean age of the respondents was 30 and 52.6% reported a college degree. Survey result illustrates nearly 90% have a good understanding about genetics studies with proportion higher than 75%. Overall differences in genetic knowledge responses were observed among different ages and educational level. Majority of the participants (82.2%) had positive attitudes toward taking part in genetic research that had exceeded the percentage Motivation score of >75%. Besides, >90% participants were willing for acquiring therapeutic benefit or continued aftercare and follow-up. However, 54.6% participants worried about Side effects as well as the risks of genetic testing and 71.4% were lacking about genetic research knowledge. Barriers were more likely among younger (<20 year) participants 44.4% (p=0.015) and low education level 29.0% (P <0.001). Moreover; Marital status and gender had no significant association. The Barriers and motivation reported by participants are summarized in Table 1 and 2

Table 1: Barriers

Barriers	Percentage %
worried about the risks	54.6
Lack of time during clinic visit.	67
Lack of knowledge	71.4

Table 2: Motivation

Motivation	Percentage %
Therapeutic benefits.	96.1
A personal interest in a particular disease.	90.7
Knowing that there would be continued aftercare and follow-up.	91.0

Conclusion

- Respondents reported relatively high knowledge about genetics research as well as high motivation for participation.
- The majority of participants reported therapeutic benefit as motivation for participation
- The fear from side effects is the predominant reason reported as barriers.
- Lack or limited knowledge and misunderstanding of research is another reason for unwillingness.
- One of the social strategies to be adapted is to increase community awareness about the role of genetic research in improving health care.

Translational Potential

- Improving awareness about genomic research is the primary factor in improving the recruitment process in the future .
- Highlighting the role of genomic research in ameliorating health care will have a positive impact on participation decisions of patients.

References

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