

## **CHARITABLE MEDICAL RESEARCH FOUNDATIONS; TOWARDS THE ESTABLISHMENT OF NON-GOVERNMENTAL RESEARCH FUNDING BODIES**

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### **ABSTRACT**

Medical research funding is an essential factor in the development of medical research field in Saudi Arabia. Governmental funding is the almost the only source of support to researchers in universities and research institutes. In developed countries, several sources of funding represents a large percentage of the total research funds. Mainly, charitable medical research foundations based on donation from the public is a main source for funds for medical research. In this work, we recognized the lack of such funding entities and investigated the main

pathway towards the establishment of alternative source of funding. A random sample of the public were recruited and the results were informative. We found that the general understanding of the public of the field of medical research was lacking. However, awareness regarding the importance of medical research and willingness to participate in such initiative was positive. The public did not have enough information on how to do so but re willing to learn about it. A small percentage of the sample thought that public funding of medical research is important. Additionally, information were lacking regarding the already functioning medical research funding charities. It is recommended therefore to establish regular public campaigns to raise awareness towards the funding of medical research. Using the media and personal contact with the public was found to be the most important factors as suggested by our results. Establishment of alternative medical research funding foundations is important in support of governmental funding. We also propose that raising the awareness of people can provide the cornerstone in this process. This can help improve the productivity of medical research in Saudi Arabia.

**KEYWORDS:** Medical research funding medical research in Saudi Arabia.

## INTRODUCTION

Medical research can improve the health of the people, fuel the economy and support innovation. Researchers in hospitals, universities and research institutions depend on funding from the government, the industry or from independent research funding foundations. However, more than 90% of the funded research in Saudi Arabia receives its funding from the government. External grants can help covering the expenses of executing a research project. This report will establish necessary information regarding the public awareness of the importance of this field. Additionally, we will investigate the willingness of the people to invest in the future biomedical advancement of this country and define the factors that can affect this decision, as a step forward towards the establishment of independent medical research funding foundations in Saudi Arabia.

The expenditure on medical research can be significantly augmented by alternative routes of funding, such as independent research foundations. The potential impact of future medical discoveries on patients, their families and on the economy is enormous.<sup>[1]</sup>

Saudi Arabia spends approximately 2.1% of the gross domestic product in 2015 on scientific research.<sup>[2]</sup> While in developed countries, the UK for example, there are always variable sources of funding. Different funding bodies respond to different influences, priorities and motivations, resulting in highly efficient medical research funding at all stages of research projects. This will also ensure continued attraction of the very best professionals into the medical research field.

Private support to international development has become increasingly important in recent years, from major charitable trusts and foundations injecting funds into global health, to businesses and corporations financing support programmes under corporate social responsibility.<sup>[3]</sup>

Biomedical knowledge is for the public good, available to any individual even if that individual does not contribute to it. Donating for research is a critical way to support this important field. The current social norm is that people donate only for religious and humane reasons. Such a shift would be of great aid to the progress of biomedical research, eventually making our society significantly healthier and longer-lived.<sup>[4]</sup>

The aim of this work is to evaluate the response of individuals to the creation of research funding foundations for health and medical research, to assess the willingness of the public to contribute and the factors that would influence people to donate to such foundations.

## **METHODS**

This cross-sectional descriptive study was conducted on the general population from Al-Madinah Al-Munawwarah, Kingdom of Saudi Arabia in June - July 2016. Data were collected from 261 adults selected randomly. The sample was selected with considerable level of variability. Males and females, singles and married individuals were recruited. The level of education and income were observed to ensure the sample was sufficiently variable to include a range of intellectual and economic classes.

An electronic questionnaire was developed after comprehensive literature review. The questionnaire was designed in Arabic language to collect information from individuals regarding age, gender, social status, education, degree of acceptance of donation, ways to increase donation, knowledge about medical research, motivations, barriers that affect the community decision to donate and questions testing the general knowledge of public research funding foundations and charitable trusts. The participation was voluntary and personal agreements consents were taken before the study.

Approval was taken from the ethics committee at faculty of medicine, Taibah University. Ethical consideration was considered to avoid any harm resulting from the study questionnaire. The confidentiality and privacy of the collected data were ensured through the use of anonymous questionnaire and during data entry and analysis. People were provided with information on the study background, aims and methods. Data were presented using mean and standard deviation as appropriate. Statistical analysis was performed using paired t-test to compare the studied outcome variables. The level of statistical significance was defined as  $P \leq 0.05$ .

## **RESULTS**

Ages participating in this questionnaire were 60% between 20 and 30 years old. This complies with the age distribution in the Saudi population, where this age range is corresponding to the highest population according to official statistics in 2015. Those older than 30 years and those younger than 20 years were around 26% and 14% respectively (Figure 1).

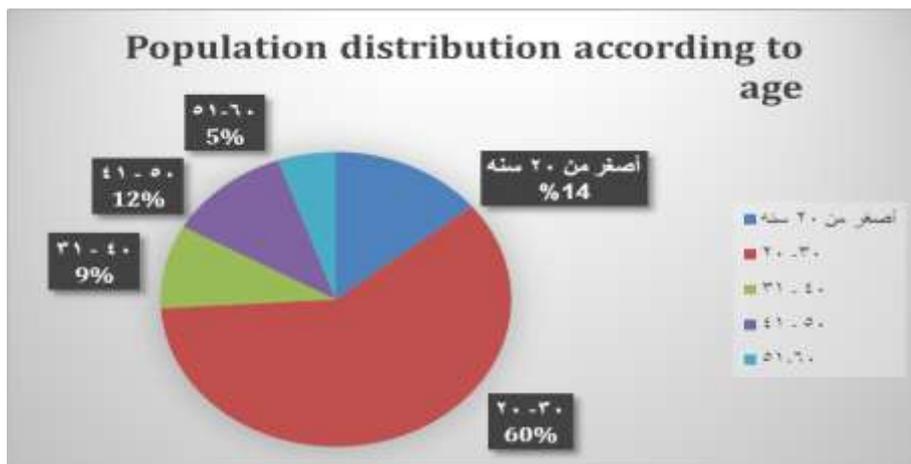


Figure 1.

It was confirmed by most of the participants that it is important to spend on medical research. The results were in favour of ‘strongly agree’ as the result was statistically significant ( $P \leq 0.001$ ).

Regarding the possible ways to increase investment in the medical research sector, we obtained a range of opinions. About 76.6% of the suggestions were directed towards the support of researchers by research institutes, hospitals and the community. Around 72% of the sample thought that the government should increase investment in medical research. More than 41% of the sample were in favour of three main pathways to support medical research. Those are; first, raising awareness towards the importance of medical research within the healthcare sector and among the public. Second was to start campaigns to raise funds. The third suggestion was to raise awareness to this issue through the media (Figure 2).

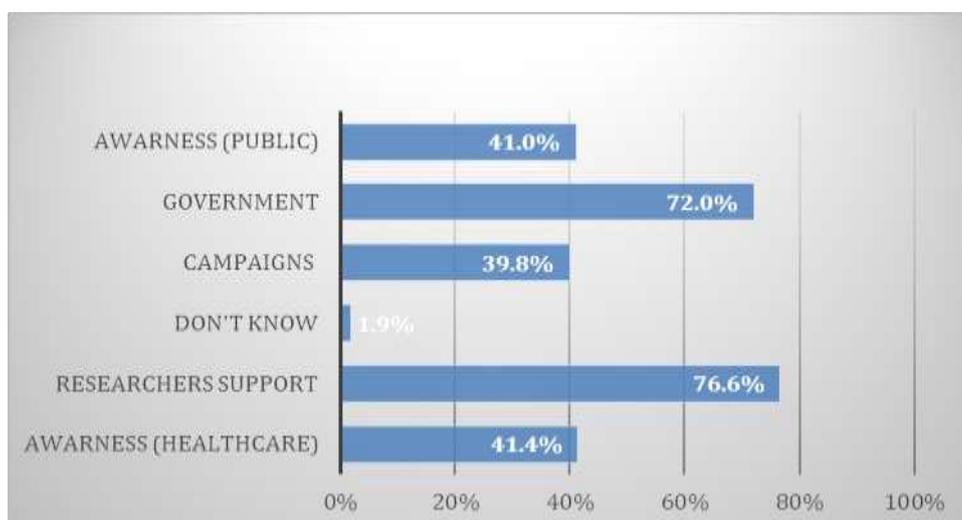


Figure 2.

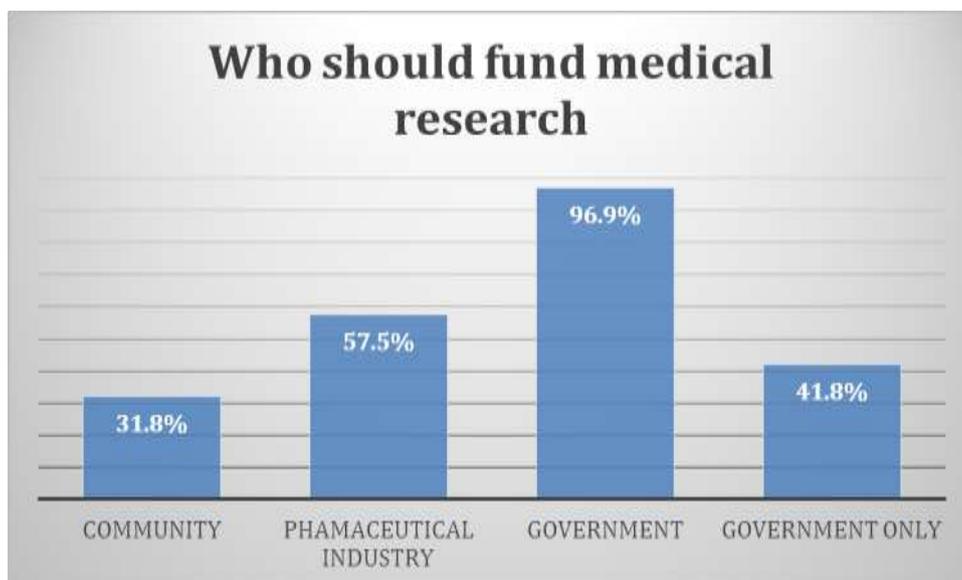
Testing the public knowledge regarding the importance of medical research, 93.5% recognized that medical research is important in finding new therapies for diseases. Between 54% and 60% knew that medical research is also important for understanding diseases, and that it is carried out by researchers and healthcare professionals and can improve general health of the nation. However, the public awareness was low regarding the 54% of the sample who thought that medical research is aimed at educating the public about diseases and how to avoid them. This is thought to be one of the goals of healthcare professionals and not researchers. However, there is a current opinion that researchers should be involved to some extent in raising the awareness of the public regarding medical research but educating the public is a different issue (table 1).

What is medical research	
Did not hear of it before	7.6%
Understanding diseases	59.4%
Educating the public	55.6%
Carried out by researchers	59.4%
Improve public health	54.0%
Finding new therapies	93.5%

Regarding the factors affecting the productivity of medical research, 45.2% thought that organization is an important factor, 75.1% believed that the scientist factor is a major player, 64.8% public support, 59.4% the idea upon which the research is carried out, 31.4% the research institute and 61.7% thought that the sufficient funding is important. Overall, the public awareness regarding the factors for a successful medical research was satisfactory. On the other hand, only 58.4% of the sample knew about any recent publication regarding a new therapy or new medicine. However, the standard deviation was 49.3 reflecting the lack of information in this area. On the other hand, the positive point is that a significant number ( $P \leq 0.001$ ) of the public participating in this study agreed to personally donate to medical research funding bodies (80%).

The suggestions of the public, as measured by our sample, to increase social, health and economical outcome of the sector of medical research were in favour of increasing the governmental funding of medical research (75.9%), while importing professionals from

abroad was the less favourable option (27.2%). When we asked a direct question regarding who is responsible for funding medical research, 96.9% answered mainly the government, 31.8% answered 'only' the government, 41.7% the public and 57.5% pharmaceutical companies (figure 3). The opinions reflected good understanding of the role of private and public research funding as an alternative or supportive solution to governmental funding.

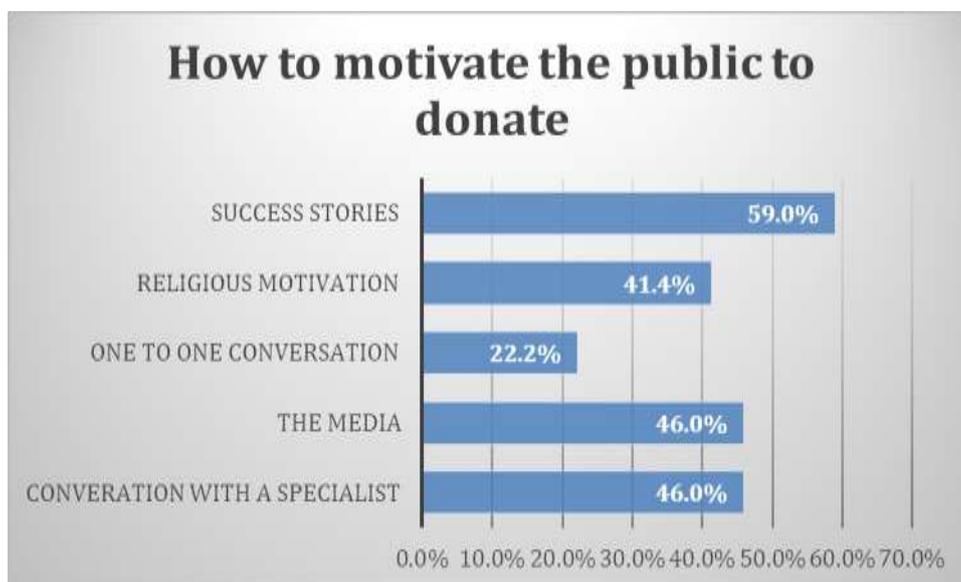


**Figure 3.**

There is also a clear shortage in the information regarding medical research funding bodies other than the government, as more than 90.8% did not know any of these bodies ( $P \leq 0.001$ ). Majority of the answers indicated that they did not donate to this cause before because they did not know where to donate and how the money will be spent. This indicated the need for organised campaigns to raise the awareness about medical research. The significant number of participants ( $P \leq 0.001$ ) in this questionnaire strongly agreed on the fact that personal contact between a campaigner and the public can significantly derive the community to donate to this cause. Additionally, they thought that medical research can significantly yield economic benefits.

To investigate the best ways to motivate the public to donate to medical research, we found the following: success stories of patients who benefited from a newly discovered medicine was found to be the most successful way to motivate the public towards donation to medical research (59%). Other important methods are to employ the media and to make campaigns to give the chance of researchers and healthcare professionals to speak to the public and show the importance of medical research. Religious factors are also very important as 41.4% of the

sample thought that they would donate if a relation was shown between religious motivations and donating to medical research (Figure 4).



**Figure 4.**

## DISCUSSION

Medical research is important in many ways. It can improve the health of people, support innovation and provide necessary information about diseases and find new treatments and medicines. However, there is a significant lack of alternative funding in the KSA, where the government is supporting most of the research activities.

This study mainly focused on measuring the public knowledge about the importance of medical research as well as the awareness and attitude toward donation for medical research. The result of this study indicated that most of the participants agree that it's important to donate for medical research and showed many different ways to increase investment on this field. But it also showed that majority of the sample did not actually donate before. This, in addition to the fact that 34.9% thought that researchers fund their work from their private money, indicated that the public awareness towards the funding of medical research by public funding bodies and charities are lagging behind. In developed countries, the governmental funding is a main player but not the only one. In some cases, public funding bodies is the main source for medical research in addition to governmental funding.<sup>[5]</sup> In addition, in our case, pharmaceutical industry is not a source of funding as most of the medicines are imported with few factories which does not invest in medical research. Clearly, the public

demands more support from the government and to count on national experiences rather than importing knowledge and foreign minds.

Previous investigations have shown that in the UK the science and research field got its strength from the diversity of funding bodies ranging from the private, public to charity foundations.<sup>[6]</sup> Another study showed the Australian model for funding medical research and it clearly indicated that majority thought that they should donate.<sup>[7]</sup> These researches agreed with our result regarding awareness and willingness of people to donate for medical research. But on the contrary to these findings, our results showed that our society has shortage in funding bodies and people who are willing to donate but they did not know how and where to donate. Additionally, there was a lack of support and foundations who can direct them to the appropriate way to support this cause.

## CONCLUSION

This study aimed to test the general knowledge of the funding of medical research, in particular, donation to medical research. We found that the population recognized the importance and value of medical research, however, guidance to how and where to donate is required. Additionally, we found a clear lack of knowledge regarding how funds are used. Building trust bridges between the public and medical research funding bodies is required to address this point. Alternative funding sources, other than governmental funding, are important to help the development and progress of this sector in Saudi Arabia.

It is recommended to initiate public campaigns to raise awareness towards the support of medical research in general and to establish research funding bodies and foundations. This can help develop the national medical research by providing alternative funding sources and therefore, improve the productivity of medical research in Saudi Arabia.

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