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Citizens' Participation in Health and Scientific Research in Switzerland

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Abstract. Understanding motivation and resistance factors affecting citizen participation in health and scientific research allows to find solutions to improve citizen engagement and interest in science. Through a survey, we identified the main factors influencing citizens' participation in scientific research, and their wishes to be more informed. Results show that the respondents' reasons to participate in research were altruistic motivations, in line with other studies carried out in developed countries. The main factor influencing the non-participation is the lack of opportunity, highlighting the importance to better inform citizens about ongoing studies.

Keywords. Community participation, motivation, attitude, research, clinical trial, ethics, global health

1. Introduction

Reasons why citizens participate or not in scientific research have been studied in the fields of sociology and psychology. While research has been conducted on motivational engagement in research in Europe [1-3], Brazil [4] and USA [5], no studies have yet investigated the context of Switzerland.

Switzerland is a country with a specific legal context. As not being part of the European Union, it does not have to comply with the same legal framework. However, following the General Data Protection Regulation (GDPR) in Europe [6], a Swiss Federal Act on Data Protection has been created. The relation of the Swiss citizens to their personal data might be country specific and it may have an impact on their willingness to participate in scientific studies.

In this paper, we describe a survey that was developed to understand the motivation and resistance factors affecting citizen participation in health and scientific research but also their wish to be more informed. It aims at understanding the processes behind these decisions and to gain an insight on how to improve this situation.

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2. Methods

We developed a survey with questions related to motivational and resistance factors that may affect citizen participation in health and scientific research. Questions and multiple-choice answers were derived from a literature review to identify factors that motivate or dissuade people to participate in scientific studies and clinical trials. The survey was distributed in French to citizens during two general public events held between July and November 2018 in Geneva (Switzerland), aimed at raising citizens' awareness about science.

The survey was separated into three parts: 1) What are their motivations to participate in scientific studies (e.g. surveys, psychology's experiments) and/or clinical trials? These questions were multiple choices with several possible answers. 2) Why did they never participate in scientific studies and/or clinical trials? These questions were also multiple choices with several possible answers. 3) What do they want to be informed about?

Concerning parts 1 and 2, since several answers were possible, the number of responses to each question was divided by the total number of responses to all the proposed answers. This allowed us to compare response frequencies out of a total of 100%.

3. Results

A total of 124 participants completed the survey. 52% were women (n=64), 46% were men (n=57) and 2% (n=3) did not answer to this question. The mean age was 43 years old. The majority of participants were Swiss (66%) and French (18%). Concerning the level of education, 1% of respondents (n=1) did compulsory school, 11% (n=14) went to high school, 72% (n=89) have a higher or university level, and 16% (n=20) did not answer.

58% (n=72) of participants reported they had already participated in a scientific study (e.g. questionnaires, psychology's experiment) while the remaining 42% (n=52) had never participated in a similar study. Among the participants who already participated in a scientific study, 60% (n=43) had participated in questionnaires, 63% (n=45) in an experiment and 19% (n=14) in another type of survey (e.g. interviews). Concerning clinical trials, 9% (n=11) of the respondents stated they had participated in a clinical trial.

3.1. Motivations to participate in scientific studies and clinical trials

Scientific studies

They were 72 responders to the question about the motivations to participate in scientific studies. Figure 1 shows that the motivational factors most often chosen were "to help the science" (30%), followed by "to help the organizer of the study" (25%) and "to help people concerned by purpose of the study" (21%). "Financial compensation" represented only 11% of the responses, followed by "to help relatives concerned by the purpose of the study" (5%), "I'm directly concerned by the purpose of the study" (4%) and others (4%).

Clinical trials

They were 11 responders and figure 1 shows that the main motivational factors concerning the participation in clinical trials were "to help the science" (28%), followed by "to help people concerned by the purpose of the study" (24%) and "to help the organizer of the study" (24%). "Financial compensation" and "I'm directly concerned by the purpose of the study" represented only 10% of the responses, followed by "to help relatives concerned by the purpose of the study" (4%).

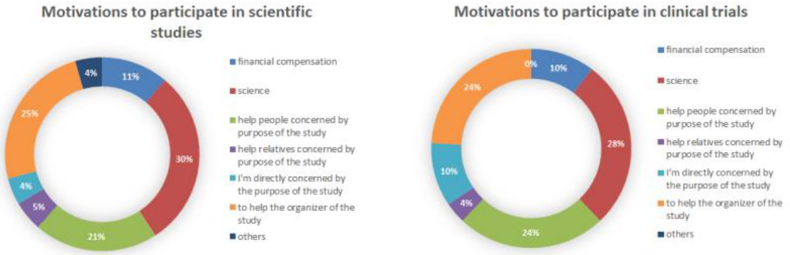

Figure 1. Distribution of motivations to participate in scientific studies (left) and clinical trials (right)

3.2. Resistance to participate in scientific studies and clinical trials

Scientific studies

The total number of respondents to this question were n=52. Figure 2 shows that the main resistance factor influencing the non-participation in scientific studies was the lack of opportunity (86%), followed by the lack of time (6%) and "the fear of what could happen to me" (4%). "The fear that confidentiality and anonymization of my data are not respected" and "the lack of interest for the subject" both represent only 2% of the responses.

Clinical trials

The total number of respondents to this question were n=111. Figure 2 shows that the main resistance factor influencing the non-participation in clinical trials was also the lack of opportunity (69%), followed by "the fear of what could happen to me" (19%). The lack of time represented 6% of the answer followed by "The fear that confidentiality and anonymization of my data are not respected" (5%). The lack of interest for clinical trials represented 1% of answers.

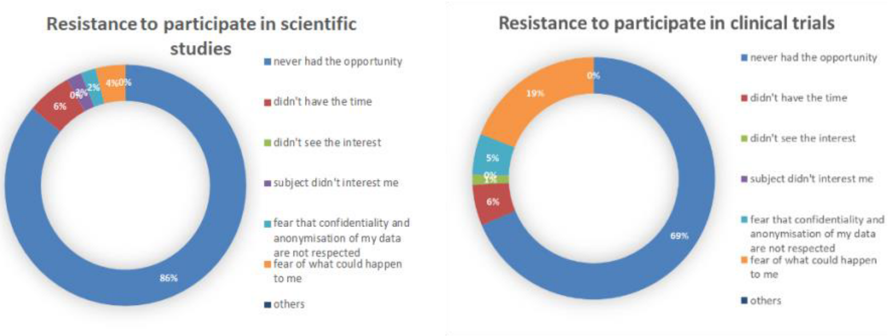

Figure 2. Resistance to participate in scientific studies (left) and clinical trials (right)

3.3. Willingness to be informed about scientific and health research

78% of the participants expressed their willingness to be informed about scientific studies going on in Switzerland. Concerning clinical trials, 70% of participants expressed their willingness to be more informed. Regarding the willingness to be informed about the results of scientific studies, results are quite similar with 77% of positive answers. Concerning results of clinical trials, 71% of respondents answered positively.Regarding more information about ethical committee, 58% of respondents answered positively. 61% of respondents expressed their willingness to be more informed about data privacy management. Finally, regarding more information about data anonymization management, 60% answered positively.

4. Discussion and conclusion

The most frequent motivational factors to participate in scientific studies and clinical trials could be defined as altruistic motivations (e.g. help the science, the people concerned by the purpose of the study and the organizer of the study). These findings are in line with other studies demonstrating that altruistic motivations are the most important motivational factors in developed countries [1, 2, 5].

Individualistic motivations were rarely mentioned in our study both for scientific research and clinical trials, in contrary to other studies where financial compensation was the main motivational factor to participate in health research [7]. According to studies, low educational level and low socio-economic status and young age appear to have a positive link with financial incentives [7, 8]. Our finding can be explained by the high educational level (72%) of our respondents. The main factor influencing the non-engagement on scientific research or clinical trials was the lack of opportunity. This finding is in line with other researches [3, 9] and highlights the need to better inform citizens about ongoing studies. Moreover, the high percentage of respondents that would like to be more informed about ongoing studies, their results, data privacy management, data anonymization management and ethical committee, shows the poor communication between scientific community and citizens. The second factor influencing the choice not to participate in clinical trials was the fear of what could happen (19%), which was much higher than for scientific studies (4%). This result is in line with findings of other studies, underlining that the psychological or physical risks to enroll in clinical trials were one of the major reasons to decline participation [10-11].

It is therefore important to clearly explain the risks and benefits to participants in an understandable language intended for lay people.

Some limitations should be taken into account regarding the results' interpretation. The high frequencies of altruistic motivations compared to individualistic motivations may be partly due to the social desirability bias driving respondents to be viewed favorably [12]. Moreover, respondents were recruited using convenience sampling method (by physical location) during events aimed at raising citizen's awareness about science. This method may impede the generalizability of the results [13]. Also, the number of respondents who participated in clinical trials was low (n=11). Therefore, a broader study needs to be performed.

In conclusion, these results show that to improve citizen participation in scientific studies, the focus should primarily be put on communication to reduce the lack of opportunity. Being able to explain research and science better to lay people as well as the implications of participating in a study is crucial. New initiatives around general and dynamic consent could help to move forward on this topic.

5. Funding

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References

[1] M. Dixon-Woods, C. Tarrant. Why do people cooperate with medical research? Findings from three studies. *Social science & medicine* **68** (2009), 2215-2222.

[2] L. Baker, T. Lavender, D. Tincello. Factors that influence women's decisions about whether to participate in research: an exploratory study. *Birth* **32** (2005), 60-66.

[3] L. Almeida, B. Azevedo, T. Nunes, M. Vaz-da-Silva, P. Soares-da-Silva. Why healthy subjects volunteer for phase I studies and how they perceive their participation?. *European journal of clinical pharmacology* **63** (2007), 1085-1094.

[4] S. A. Nappo, G. B. Iafrate, Z. M. Sanchez. Motives for participating in a clinical research trial: a pilot study in Brazil. *BMC Public Health* **13** (2013), 19.

[5] M. C. Soule, E. E. Beale, L. Suarez, S. R. Beach, C. A. Mastromauro, C. M. Celano, S. V. Moore BA, J. C. Huffman. Understanding motivations to participate in an observational research study: Why do patients enroll?. *Social work in health care* **55** (2016), 231-246.

[6] P. Voigt, A. Von dem Bussche. The eu general data protection regulation (gdpr). *A Practical Guide, 1st Ed., Cham: Springer International Publishing* (2017).

[7] L. Stunkel, C. Grady. More than the money: a review of the literature examining healthy volunteer motivations. *Contemporary clinical trials* **32** (2011), 342-352.

[8] N. E. Kass, R. Myers, E. J. Fuchs, K. A. Carson, C. Flexner. Balancing justice and autonomy in clinical research with healthy volunteers. *Clinical Pharmacology & Therapeutics* **82** (2007), 219-227.

[9] K. Lowton. Trials and tribulations: understanding motivations for clinical research participation amongst adults with cystic fibrosis. *Social Science & Medicine* **61** (2005), 1854-1865.

[10] K. A. Cunny, H. W. Miller. Participation in clinical drug studies: motivations and barriers. *Clinical therapeutics* **16** (1994), 273-82.

[11] E. Novak, C. E. Seckman, R. D. Stewart. Motivations for volunteering as research subjects. *Journal of Clinical Pharmacology* (1977).

[12] O. Sjöström, D. Holst. Validity of a questionnaire survey: response patterns in different subgroups and the effect of social desirability. *Acta Odontologica Scandinavica* **60** (2002), 136-140.

[13] A. S. Acharya, A. Prakash, P. Saxena, A. Nigam. Sampling: Why and how of it. *Indian Journal of Medical Specialties* **4** (2013), 330-333.