A Survey of Self-Perceived Knowledge and Knowledge Gaps of Medicines Research and Development Among Finnish General Public

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Abstract

Background: This study explored self-reported knowledge and willingness to learn more about medicines research, development and health technology assessment among Finnish general public. It also aimed to define possible knowledge gaps and needs for public education regarding medicines research, development as well as health technology assessment.

This questionnaire was originally developed as a part of the Needs Assessment Work Package of the European Patients' Academy on Therapeutic Innovation (EUPATI) Project. The questionnaire was translated from English to Finnish and the survey was carried out in Finland in 2019.

Methods: The survey was conducted as an online survey by Kantar TNS Gallup Forum online panel. The data was analyzed by using the freely available R program. Relationships between the demographic characteristics (such as age, gender and education level) of respondents and their knowledge or interest in medicines research and development were determined using Pearson's chi-squared tests.

Results: Of the 503 respondents (age 16-64) only 12% reported having good or very good knowledge of medicines research and development in general. Regarding health technology assessment, pharmacoeconomics and regulation, the percentage of respondents reporting good or very good knowledge was as low as 8%.

Respondents were most interested in learning more about predictive and personalised medicine (47 %) and least interested in medicines regulation (30%) and pharmacoeconomics (31%). Those who had participated in a clinical trial had better knowledge and were significantly more interested in learning more about several aspects of medicines research, development and health technology assessment.

Conclusions: Self-reported knowledge about medicines research and development and health technology assessment appears to be very low in Finland. Patient and public participation is recognized as an important and essential element in up-to-date medical research and assessment of new treatments. In order to participate as an active and equal partner in these processes, the public needs more information and education in these topics.

Trial registration

Not applicable

Background

Participation of patients and the general public in medicines research and development (R&D) and health technology assessment (HTA) can produce a wide range of benefits. For example, by helping the researchers to understand the needs and priorities of the patients, it yields more relevant outcome measures and better treatment adherence and may also increase both public trust and interest towards medicines R&D (1-6).

As authorities, research groups and research funders are increasingly understanding the importance of patient and public involvement (PPI), it is gradually becoming an integral part of both medicines R&D and HTA processes (2, 7-10). So far in Finland the public participation into medicines R&D and HTA has been rather minimal and only recently, academic research groups and national HTA bodies such as the Pharmaceuticals Pricing Board and Council for Choices in Health Care in Finland have started to open some of their processes for PPI (10-13). However, the implementation of PPI in medicines R&D and HTA requires that the public has sufficient knowledge of its concepts, methods, benefits and rationale as well as its challenges. The aim of this research was to study the self-reported

knowledge of the Finnish public on both medicines R&D and HTA and to define the possible knowledge gaps and needs for public education.

This survey was first conducted in six European countries as a part of the Needs Assessment Work Package of the European Patients' Academy on Therapeutic Innovation (EUPATI) Project and its results were published in 2015 (14). The survey was translated from English to Finnish and replicated in Finland in 2019.

Methods

Questionnaire

The original survey questionnaire was translated from English into Finnish by using the back-translation method and piloted with four Finnish speaking volunteers before conducting the survey in January 2019 (14).

The survey was conducted by Kantar TNS Gallup Forum online panel, which consists of recruited adults aged 15-80 who have given their explicit permission to be contacted about surveys. Panelists are recruited mainly using telephone recruitment and the panel recruitment is constant to ensure that samples drawn from it are representative of the demographics. The total size of the panel is about 40 000 persons. Panelists are invited by email to answer the surveys. In this survey, we only included participants aged 16-64 years.

Participants were invited to answer this survey using a quota sampling approach, with quotas being set based on national census data on age, education and geographic region. Overall internet-penetration is fairly high in Finland (97 %). Therefore, using a panel gives a good chance to reach a sound representative sample of the target group.

Statistical analyses

The statistical analyses and data visualisation were performed on R version 3.6.0 (15). The relationships between the demographic characteristics (age, gender, education, participation in a clinical trial) of respondents and knowledge or interest in medical research were determined using Pearson's chi-squared tests. Statistically significant responses were determined by logistic regression. The distribution of the responses was visualised using ggplot2 version 3.3.0 (16). The data and the analysis code are available at https://github.com/manutamminen/knowledge_and_knowledge_gaps_of_medicines_research_among_finnish_public.

Results

Demographic factors

Altogether 503 respondents (age 16-64) completed the survey. Their demographic information is presented in Table 1.

Table 1. Demographic characteristics of survey respondents

		Base= 503
		% (n)
Gender	Female	53 % (266)
	Male	47 % (237)
Age group (years)	16-24	13 % (67)
	25-34	17 % (86)
	35-44	16 % (78)
	45-54	25 % (123)
	55-64	30 % (149)
Education*	Vocational education and training	22 % (112)
	High school degree	11 % (55)
	Post-secondary education	18 % (90)
	University of Applied Science, Bachelor's degree	21 % (106)
	University degree	15 % (75)
Experience of medical research**	Yes	16 % (81)
	No	82 % (412)
*13 % participants did not indicate their education level		
**2 % of participants did not answer to this question		

Involvement in medical research

16 % of the respondents had participated in a clinical trial and this was significantly more common among males (20 %) than females (13 %), p<0.05.

Current knowledge of medicines R&D and HTA

Nearly 90 % of the respondents reported no or poor knowledge of medicines R&D in general. There were no significant differences between genders, age groups or education level, even though the self-reported knowledge of medicines R&D in general appeared to decrease by respondents age (Table 2). Respondents who had participated in a clinical trial reported significantly better knowledge (25 % reported having good or very good knowledge) than those who had not been involved in clinical trials (Table 2).

For the respondents, the most familiar topics in medicines R&D were medicines safety (good or very good knowledge 13 %), medicines development (11 %) and predictive medicine (11 %).

Regarding HTA, pharmacoeconomics and medicines regulation, only 8 % of the respondents reported good or very good knowledge (Figure 1). Good or very good knowledge regarding patients' roles and responsibilities in medicines R&D was even lower being 7 %.

Willingness to learn more

Respondents were most interested in learning more about predictive and personalised medicine (47%), and least interested in medicines regulation (30 %), pharmacoeconomics (31 %) and HTA (35 %). Females were significantly more interested in learning more about medicines safety, predictive and personalised medicine, HTA, and regulation than males ($p<0.05$; logistic regression).

Respondents who had previously been involved in a clinical trial reported significantly better knowledge ($p<0.05$; logistic regression) in most areas of medicines R&D and HTA and were more interested in learning more about pharmacoeconomics and medicines regulation than other respondents (Figure 1).

Table 2. Current general knowledge about medicines R&D

		Respondents with good or very good knowledge	p-value (χ^2-test)
	All participants	12 % (45, n=389)	
Gender	Female	10 % (20)	0.3438
	Male	13 % (25)	
Earlier participation in a clinical trial	Participated in a clinical trial	25 % (15)	0.0011
	Not participated in a clinical trial	9 % (30)	
Age (years)	16-24	21 % (10)	0.231
	25-34	12 % (8)	
	35-44	12 % (7)	
	45-54	11 % (10)	
	55-64	8 % (10)	
Education	Vocational education and training	13 % (10)	0.151
	High school degree	13 % (4)	
	Post-secondary education	9 % (7)	
	University of Applied Science, Bachelor's degree	19 % (17)	
	University degree	7 % (4)	

Sources of information

Most respondents (75%) reported using websites to find out information about medicines R&D and HTA, and 58 % reported doctors and other health care professionals to be their main source of information. Nearly a third of the respondents listed TV programs and newspapers as one source of information.

A majority, 70 % of the respondents wished to receive information about medical issues from a doctor or other health care professional, and 44 % from authorities. The least popular sources of information were friends or relatives (12 %), public-private partnerships (18 %) and pharmaceutical companies (19 %).

Discussion

According to our results, Finns estimate their knowledge on medicines R&D lower than British, French, German, Italian and Polish respondents (14). This is rather surprising as traditionally Finns have expressed strong interest towards science and research (17, 18, 19) and as health literacy is also a part of the national school curricula in Finland (20). On the other hand, so far improvement of health literacy in general has not been included into national policy programs in Finland, although this may be partly due to differences in terms and concepts (21).

As an earlier involvement in clinical research increased patients self-reported knowledge and willingness to learn more about certain aspects of medicines R&D and HTA, our results imply that participation into a clinical research has been an educating and perhaps also an empowering experience for the participants (14).

Respondents of this study were most interested to learn about personalised and preventive medicine – contents essential in both Finnish Health Sector Growth Strategy for Research and Innovation Activities and in Finland's Genome Strategy (22, 23). As the Finnish Government has recently decided to support the Health Sector Growth Strategy in 2021-2022 with an additional funding (24), these topics have also been discussed in the mainstream media, perhaps partly explaining the public interest towards them. Currently Finland is implementing several public-private research projects on personalised and predictive medicine, such as FinnGen, which aims at improving human health through genetic research and iCAN Digital Precision Cancer Medicine Flagship, which integrates precision medicine and digital health data for development of personalised cancer treatments (25, 26). Despite this, the self-reported knowledge regarding preventive medicine and genomics are rather low among Finnish public (27) and hence the importance of increasing the capacity of healthcare professionals to apply genome-based information as well as the empowerment of the public in improving their own health by effective use of genomic information is being emphasized for example in Finland's current Genome Strategy (23).

Pharmacoeconomics and HTA were the least interesting topics for respondents in this survey. One explanation for this might be that the Finnish HTA system is extremely fragmented and there is an ongoing discussion and several recommendations to simplify the system (28, 29). The Finnish Medicines Agency Fimea has published a recommendation to integrate patient perspectives into HTA process of pharmaceuticals (7, 30). However, this plan has not been fully realized yet. Currently patient organisations and the general public can only leave their comments on recommendation drafts prepared by the Council for Choices in Health Care, and provide some input for the Pharmaceuticals Pricing Board when they are assessing reimbursement statuses and wholesale prices of medicinal products (11, 12).

Preferred sources of information

In Finland, the public trust in health care services has traditionally been strong (31, 32) and our findings also indicate Finns to prefer health care professionals and authorities as the main source for health-related information. To maintain this, the knowledge-level of health care professionals needs to be kept up-to-date by organizing continuous education for them and also by allocating time and other resources of health care settings so that these complex topics can be carefully explained and discussed with patients and their caregivers (23, 33, 34).

Limitations of the study

Generalization of these results should be done with caution as the results are based on self-reported data, which might be subjected to biases such as misunderstanding of the questions asked and biases in one's memory.

Conclusions

This study indicated a need for medicines R&D and HTA related health literacy programs targeted for the Finnish general public. These programs could not only improve the level of public knowledge on medicines R&D and HTA, but also empower and increase the public interest to be involved in these processes in the future, as a potential consequence of critical health literacy (35). Just recently some advancements have been made to better inform the Finnish general public on medicines R&D and HTA as Finnish biobanks have added public information of their research and services on their websites and started to organize educational events targeting the general public (36, 37). Also, the Ministry of Social Affairs and Health has opened informative websites such as websites for the national Genome and Neuro Centers (38, 39) and the Finnish Medicines Agency Fimea set up a Patient Advisory Board which started to operate on spring 2020 (40). In addition, a national platform of European Patients' Academy on Therapeutic Innovation (EUPATI) was launched in Finland in 2018 providing patients and patient organizations with education on medicines R&D as well as HTA (41). These are important advances for educating the public on medicines use. However, if authorities, companies and researchers genuinely want to involve patients and the public in medicines R&D and integrate their contribution also in the HTA processes, there is a need to develop clear guidelines for public participation as well as increase public education on these issues. Transparent and public discussion of health care decision making and priority setting is also urgently needed (42) as new treatments are increasingly costly needing a thorough pharmacoeconomic and ethical assessment before they reach patients.

List Of Abbreviations

HTA: Health technology assessment

Medicines R&D: Medicines research and development

Declarations

Ethics approval and consent to participate

The study participants were recruited through the Kantar TNS Gallup Forum online panel. The Kantar TNS Gallup Forum online panel consists of recruited adults aged 15-80 who have given their explicit permission to be contacted about surveys. However, this survey was only targeted to participants aged 16-64 years.

The research was carried out following the ethical principles of research with human participants of the Finnish National Board on Research Integrity TENK (43). The research was conducted respecting the dignity and autonomy of human research participants, and the research complies with the guidelines on responsible conduct of research (RCR) drawn up by TENK (44). The participants were informed about the study by an electronic letter of consent, which they had to accept before entering the online survey. The researchers had no access to any personal data of the participants.

Consent for publication

Not applicable

Availability of data and materials

The dataset(s) supporting the conclusions of this article is available in the GitHub repository: https://github.com/manutamminen/knowledge_and_knowledge_gaps_of_medicines_research_among_finnish_public.

Authors' contributions

MTM, TL, JTS and MMM participated in planning and developing the survey. MT and RB conducted the statistical analyses. MTM, MT and TL drafted the manuscript. All authors read and approved the final version of the manuscript.

Authors' information (optional)

Not applicable

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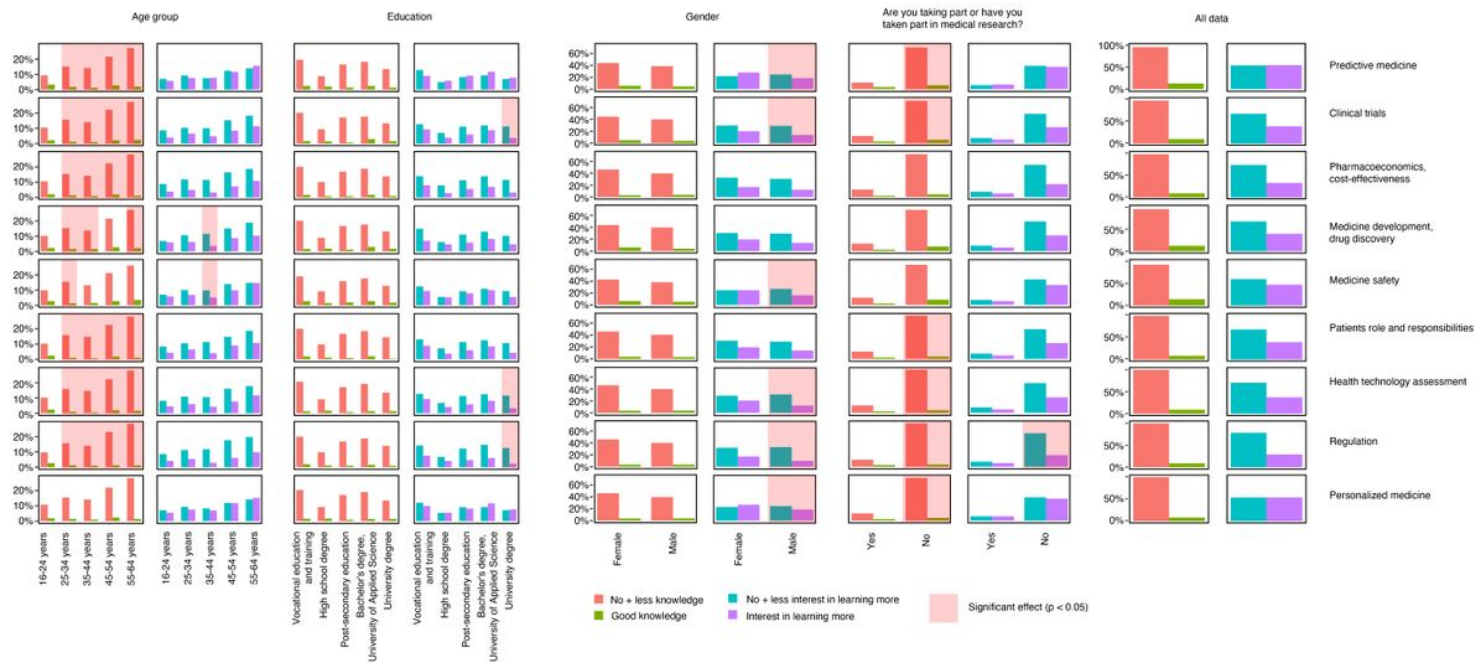
Figures

Figure 1

Distribution of current knowledge and interest in learning more about specific aspects of medicines R&D and HTA by age, education, gender and earlier participation in clinical trials. Percentages of responses (n=503) are presented in Y-axis and responses in X-axis. Statistically significant responses (logistic regression; p < 0.05) are indicated with red shading.