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Quantitative online survey of self-perceived knowledge and knowledge gaps of medicines research and development among Finnish general public

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BMJ Open Quantitative online survey of self-perceived knowledge and knowledge gaps of medicines research and development among Finnish general public

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ABSTRACT

Objectives This study explored self-reported knowledge and interest 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 these topics.

Design Online survey with 503 participants. The questionnaire was originally developed as a part of the Needs Assessment Work Package of the European Patients' Academy on Therapeutic Innovation Project. 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 were analysed by using the freely available programming language R. 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 χ^2 tests. Statistically significant responses of demographic characteristics in the respondents' knowledge or interest in medicines research were determined by logistic regression.

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, pharmacoconomics 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 pharmacoconomics (31%).

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 recognised 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.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study was conducted by a multiprofessional team including patient organisation representatives.
- ⇒ The study indicated a need for medicines research and development (R&D) and health technology assessment (HTA)-related health literacy programmes targeted for the Finnish public. The study will contribute to the future research agenda of health literacy and public knowledge on medicines R&D and HTA.
- ⇒ The sampling method ensured a representative cross-section of the adult population in Finland.
- ⇒ However, generalisation of the 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 in the survey.

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 low and only in recent years, academic research groups and national HTA bodies such as the Pharmaceuticals Pricing Board and Council for Choices in Healthcare

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 survey¹⁴ (online supplemental materials questionnaire).

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. Panellists 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. Panellists are invited by email to answer the surveys.

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 geographical 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. The survey was open from 24 January to 30 January 2019.

Statistical analyses

The statistical analyses and data visualisation were performed on R V.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 χ^2 tests using function `chisq.test` implemented in R library `stats`.¹⁵ Statistically significant responses were determined by logistic regression using function `glm` implemented in R library `stats`¹⁵ and using age group, education, gender and medical research participation as explanatory variables. The distribution of the responses was visualised using `ggplot2` V.3.3.0.¹⁶ The data and the analysis code are available in a public, open access repository.¹⁷

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	24% (123)
55–64	30% (149)
Education*	
Vocational education and training	22% (112)
High school degree	11% (55)
Post-secondary education	18% (90)
Bachelor's degree or equivalent	21% (106)
Master's degree or higher	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.

PPI statement

This study has been planned and conducted by the members of the EUPATI Finland executive committee / Association of Cancer Patients in Finland, including and led by patient organisation representatives. The survey was pretested by patient group members, and the results will be distributed in lay language in patient organisations' channels.

RESULTS

Demographic factors

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

Involvement in medical research

Sixteen per cent 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

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)	
Bachelor's degree or equivalent	19% (17)	
Master's degree or higher	7% (4)	

R&D, research and development.

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; online supplemental table S1). Good or very good knowledge regarding patients' roles and responsibilities in medicines R&D was even lower being 7%.

Interest 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 medicines regulation than other respondents (figure 2; online supplemental table S1).

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 healthcare professionals to be their main source of information. Nearly one-third of the respondents listed television programmes 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 healthcare 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^{18–20} and as health literacy is also a part of the national school curricula in Finland.²¹ On the other hand, so far improvement of health literacy in general has not been included into national policy programmes in Finland.²²

As an earlier involvement in clinical research increased patients self-reported knowledge and interest to learn more about certain aspects of medicines R&D and HTA, our results imply that participation into clinical research has been an educating and perhaps also an empowering experience for the participants.¹⁴ We acknowledge that experiential knowledge (lived experience) is an essential element in PPI which complements the perspectives of healthcare and research professionals.^{23 24} We propose that both experiential and theoretical knowledge is needed for successful PPI: access to information has been found to increase self-efficacy of patient representatives and to enable balance of power to be redistributed, so that all stakeholders can contribute to decision-making process.²⁵ On the other hand, lack of knowledge has been recognised as one of the barriers for PPI.²⁵

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.^{26 27} As the Finnish Government has recently decided to support the Health Sector Growth Strategy in 2021–2022 with an additional funding,²⁸ these topics have also been discussed in the mainstream media,

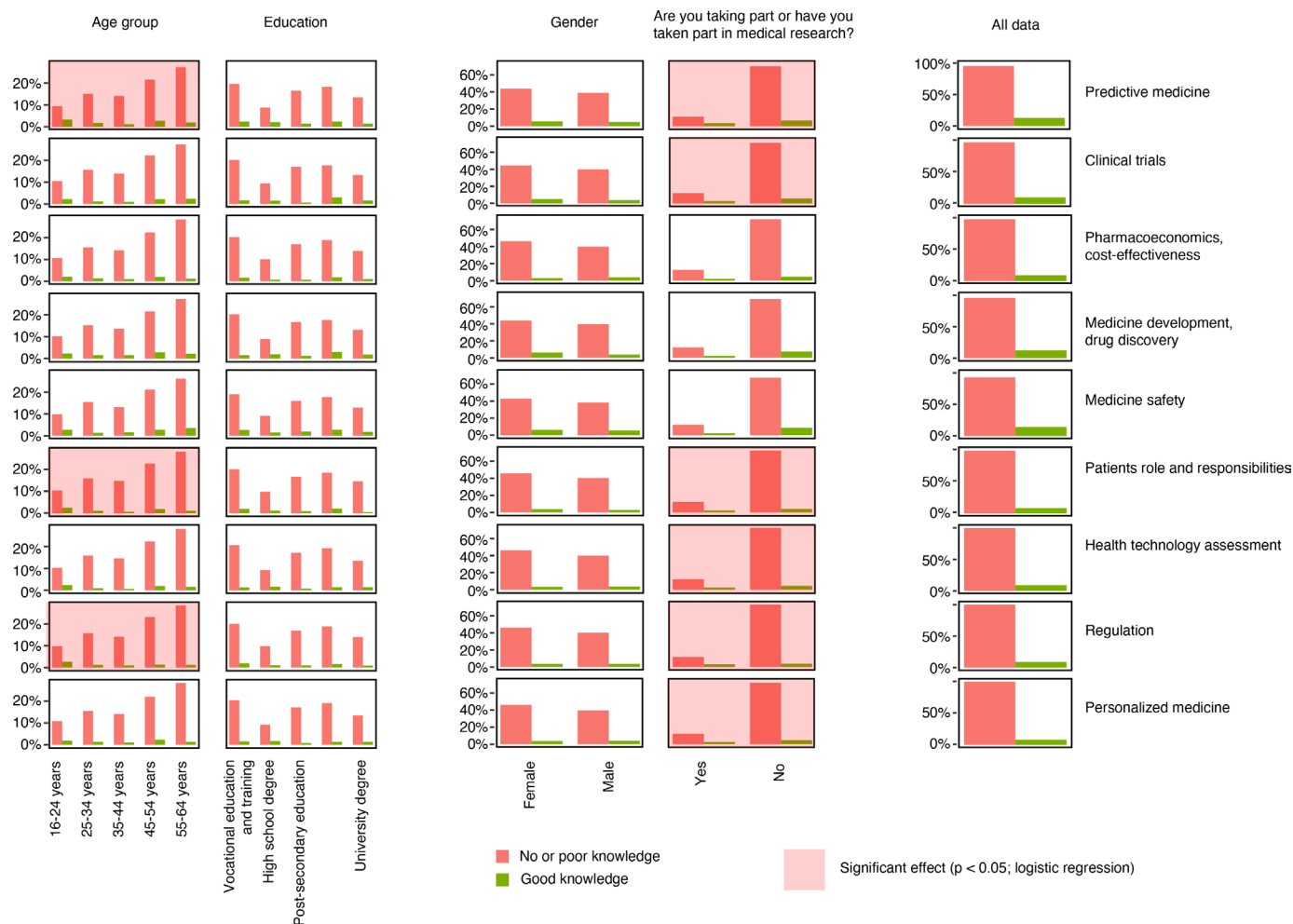


Figure 1 Distribution of current knowledge about specific aspects of medicines R&D and HTA by age, education, gender and earlier participation in clinical trials. Percentages of responses (n=503) are presented in y-axis and responses in x-axis. Statistically significant responses (logistic regression; $p < 0.05$) are indicated with red shading. HTA, health technology assessment; R&D, research and development.

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.^{29 30} Despite this, the self-reported knowledge regarding preventive medicine and genomics are rather low among Finnish public³¹ 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 emphasised for example in Finland's Genome Strategy.²⁷

Pharmacoeconomics and HTA were the least interesting topics for respondents in this survey. One explanation for this might be that the Finnish reimbursement and HTA landscape is very fragmented.³²⁻³⁴ There is currently an ongoing discussion and several recommendations to simplify the system.³⁴⁻³⁶ The Finnish Medicines

Agency Fimea has published a study and recommendation to integrate patient perspectives into HTA process of pharmaceuticals.^{7 37 38} However, this plan has not been fully realised yet. Currently patient organisations and the general public can leave their comments on recommendation drafts prepared by the Council for Choices in Healthcare, and provide 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 healthcare services has traditionally been strong^{39 40} and our findings also indicate Finns to prefer healthcare professionals and authorities as the main source for health-related information. To maintain this, the knowledge level of healthcare professionals needs to be kept up to date by organising continuous education for them and also by allocating time and other resources of healthcare settings so that these complex topics can be carefully discussed with patients and their caregivers.^{27 41 42}

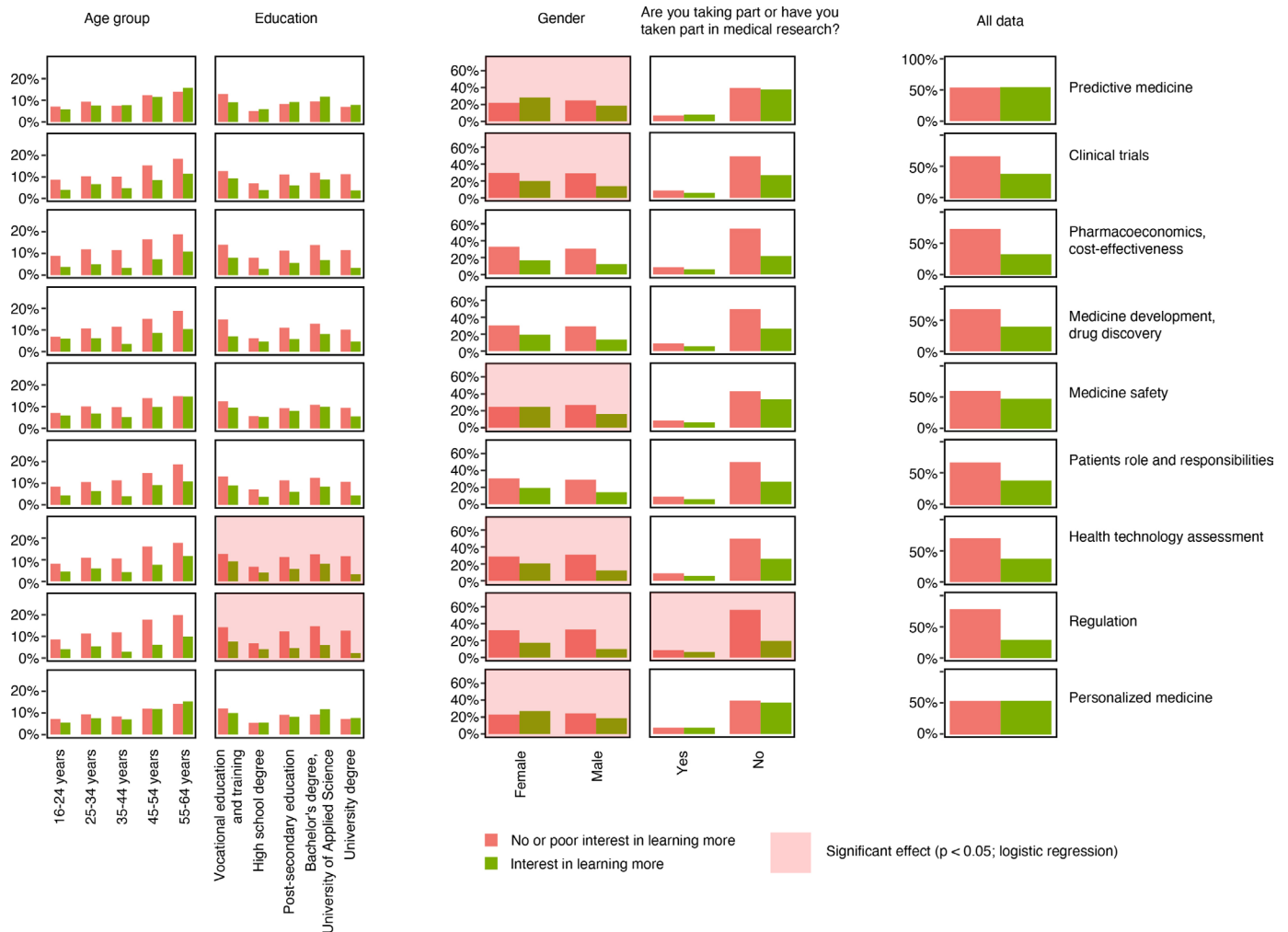


Figure 2 Distribution of interest in learning more about specific aspects of medicines R&D and HTA by age, education, gender and earlier participation in clinical trials. percentages of responses (n=503) are presented in y-axis and responses in x-axis. Statistically significant responses (logistic regression; $p < 0.05$) are indicated with red shading. HTA, health technology assessment; R&D, research and development.

Limitations

The results of this study are based on self-reported data, so generalisation of the results should be done with caution. The quotas in this survey were set based on national census data on age, education and geographical region to ensure a representative sample of the demographics. However, participants in the Kantar TNS Gallup Forum had agreed to receive survey questionnaires on various topics and therefore may not reflect the views of the general population. We also acknowledge that this volume of sampling might be insufficient in capturing thorough population level distributions and may involve biases.

This quantitative study focused on self-reported knowledge about medicines R&D and HTA. A qualitative approach would allow studying the role and impact of experiential knowledge in more depth. Also, the answers reflect the situation in one time point in early 2019. Due to the global COVID-19 pandemic, vaccine development and drug regulatory processes have been discussed in

public more than ever before. This may affect the generalisation of the results to the present date.

CONCLUSIONS

This study indicated a need for medicines R&D and HTA-related health literacy programmes targeted for the Finnish general public. These programmes 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.⁴³ 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 organise educational events targeting the general public.^{44 45} Also, the Ministry of Social Affairs and Health has opened informative websites such as websites for the national Genome and Neuro Centres^{46 47} and the

Finnish Medicines Agency Fimea set up a Patient Advisory Board which started to operate on spring 2020.⁴⁸ In addition, a national platform of EUPATI was launched in Finland in 2018 providing patients and patient organisations with education on medicines R&D as well as HTA.⁴⁹ 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 and educate healthcare professionals and researchers of the importance of PPI. Transparent and public discussion of healthcare decision making, and priority setting is also urgently needed⁵⁰ as new treatments are increasingly costly needing a thorough pharmacoeconomic and ethical assessment before they reach patients.

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Contributors MTM, TL, JT-S and MMM participated in planning and developing the survey. MT and RT conducted the statistical analyses. MTM, MT and TL drafted the manuscript, and MTM is the guarantor. All authors read and approved the final version of the manuscript.

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Competing interests MTM, TL, JT-S and MMM are members of the EUPATI Finland executive committee.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants but the study participants were recruited through the Kantar TNS Gallup Forum online panel. The research was carried out following the ethical principles of research with human participants of the Finnish National Board on Research Integrity TENK (2019). The participants were informed about the study by a 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 and exempted this study. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

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