The European Journal of Public Health Advance Access published September 29, 2016

European Journal of Public Health, 1–7

doi:10.1093/eurpub/ckw155

Current state of genomic policies in healthcare among EU member states: results of a survey of chief medical officers

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Background: A need for a governance of genomics in healthcare among European Union (EU) countries arose during an international meeting of experts on public health genomics (PHG). We have conducted a survey on existing national genomic policies in healthcare among Chief Medical Officers (CMOs) of the 28 EU member states, plus Norway. **Methods:** A questionnaire was sent to CMOs after a meeting on the policy implications of PHG held during the Italian presidency of the Council of EU in 2014. The survey was closed in November 2015. **Results:** *CMOs* response rate was 65.5% (19/29). Twelve (63.2%) reported that their countries had a policy for genomics in healthcare in place, and 15 (78.9%) reported that public funding existed. Public research facilities for the development of such policies were documented in 13 (68.4%) countries, and 15 (83.3%) had working groups devoted to policy development. National agencies carrying out Health Technology Assessment of genomic-based technologies were present in nine countries (50%). Sixteen (88.9%) countries reported having agencies dealing with ethical issues related to genomic technologies. About 55% of countries disclosed the lack of information campaigns aimed at citizens, and 44.4% reported they had a legal framework for direct-to-consumer genetic tests. **Conclusion:** Belgium, France, Italy, Spain and UK documented the presence of a policy on genomics in healthcare. While many caveats are necessary because of the methodology, results suggest a need for a co-ordinated effort to foster development and harmonization of dedicated policies across EU to responsibly integrate genomics policies into existing health systems.

Introduction

Advances in genomics have important implications for public health, for example by offering new ways of differentiating individuals and groups within populations according to their susceptibility to disease or ability to benefit from treatment.[1,2] Yet, despite rapidly advancing genomic technologies, these have, to date, received limited attention in debates on health policy.

Since 2005, a multidisciplinary group has been assessing the potential implications of genomic developments for population health, leading to the term "Public Health Genomics" (PHG), defined as "*the responsible and effective translation of genome-based knowledge and technologies into public policy and health services for the benefit of population health.*[3] In 2014, an international meeting of experts recognised the urgent need for the public health community (with its focus on population-based prevention) to engage with scientists and clinicians (with their primary focus on the individual and his or her genes) in order to maximise the potential that genomics offers for effective and equitable disease prevention and health improvement.[4]

Seeking to engage policy makers in this discussion, the Italian Ministry of Health organized a meeting in Rome in October 2014, during the Italian presidency of the Council of the European Union. The 28 Chief Medical Officers (CMO) of EU member states, plus the CMO from Norway, were invited to discuss the policy implications of advancements in genomics for health systems.[5] The meeting concluded with a call for coordinated engagement to develop policy on genomics in healthcare within the EU. To inform this process, we undertook a survey of EU CMOs, including both those present at the meeting and those unable to participate.

Methods

The survey draws on an earlier one undertaken in 2013 by the Italian Ministry of Health looking at the policies and practice relating to genomics in healthcare in EU member states, in collaboration with the Federation of European Academies of Medicine (FEAM).[6] In the present survey, W.M. and S.B. designed a structured questionnaire, containing 22 questions organized into seven sections (A–G, table 1). Section A asks about the presence, and extent, of any policy on genomics in healthcare and related financial support. Section B examines research in support of genomics policy in healthcare. Section C examines progress in developing genomics in healthcare. Section D asks about health technology assessment while Sections E, F and G exploring ethical and legal issues, education and training, and public engagement, respectively.

The 22 CMOs participating in the meeting (Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Greece, Hungary, Ireland,

Table 1 The questionnaire with twenty-two questions organized into seven sections (A–G)

Section	Question	Sub-question (where applicable)
A. Policy	**A1.a** Is there a policy concerning the use of genomics in healthcare or health services in place in your country? **A2.a** Does your country provide any kind of support for the development of policy concerning the use of genomics in healthcare or health services? **A3**. Do you know how much of the public funding during the last calendar year was devoted to the development of policy concerning the use of genomics in healthcare or health services? *(< €50 000, €50 000–200 000, €>200 000, I am not aware/not certain)* **A4.** Do you know how much of the private funding during the last calendar year was devoted to the development of policy concerning the use of genomics in healthcare or health services? *(< €50 000, €50 000–200.000, €>200 000, I am not aware/not certain)*	**A1.b** If yes, are there any specific guidelines already in place in your country? **A2.b** If yes, please provide further details about the Institutions providing support *[Selection Public and Private institutions]*
B. Research	B**1.a** Do research facilities exist in your country devoted to the development of policy or service in the use of genomics in healthcare? **B2.a** Is/Are there in your country Institution/s providing financial support to the research in policy or service development in the use of genomics in healthcare? **B3.** Do you know of any research projects on policy or service development in the use of genomics in healthcare in your country, supported by public funding? **B4.** Do you know of any research projects on policy or service development in the use of genomics in healthcare in your country, supported by private funding?	**B1.b** If yes, public or private? **B2.b** If yes, please provide further details about the Institutions providing support. *[Selection of Public and Private institutions]*
C. Progress Reports	**C1.a** Have PHG progress reports ever been published in your country? **C2.** Who has developed and published those progress reports? *(Universities, Ministry, I am not aware/not certain, Others)* **C3.** Are reports regularly developed? *(No, Less than once a year, At least once a year)* **C4.** Could you provide information about the most recently published report? (title, authors, publication year), link(s) to the web page(s), and the institutions providing them	**C1.b** If yes, whom are they addressed to? *[Selection of stakeholders]*
D. Technical Facilities	**D1.** Are there national groups (agencies, technical/professional working groups, commissions, etc.) working on policy or service development in the use of genomics in healthcare in your country? **D2.** Are there national agencies carrying out national Health Technology Assessment and/or horizon scanning on genome-based technologies in your country? **D3.** Are there regional groups (agencies, technical/professional working groups, commissions, etc.) dealing with policy or service development in the use of genomics in healthcare in your country? **D4.** Are there regional agencies carrying out the National Health Technology Assessment and/or horizon scanning on genome-based technologies in your country?	
E. Ethical Implications	**E1.** Are you aware about the existence of departments/agencies at the national or regional level discussing the ethical issues and/or legal matters related to the use of genomics in healthcare in your country? **E2.** Are you aware about the existence of departments/agencies at the national or regional level whose expertise might be included in the discussion of ethical issues and/or legal matters related to policy or service development in the use of genomics in healthcare in your country?	
F. Education and Training	**F1.** Do you know if the issues surrounding the use of genomics in healthcare are taught in health-related university courses, either in the form of seminars, teaching modules or as a specific subject, in your country? *(Yes, in pre-graduate courses, Yes, in post-graduate courses, No)* **F2.a** Are specific training courses available for health professionals with particular regard to the correct use and proper prescription of susceptibility testing[a] (for complex disorders) in your country?	**F2.b** If yes, for which professional categories are they addressed to? *[Selection of professional categories]*
G. Citizens	**G1.** Has your country ever established information campaigns (advertising on billboards, campaigns, commercials, TV or radio, etc.) on susceptibility tests (for complex disorders)? **G2.** Has your country adopted a legal framework, professional and other guidelines or developed ethical opinions for the use of Direct-to-Consumer Genetic Tests?	

a: Susceptibility testing (also known as predisposition test) detects genetic variants that are associated with an increased risk of disease but cannot predict with certainty the development of disease, because of the incomplete penetrance of the genetic mutation.

Table 2 Answers to the survey questions according to the A–G sections

Questionnaire section	Question no.	No. of responding countries	Yes (%)	No (%)	Not aware (%)
A. Policy	**A1.a**	19	12 (63.2)	7 (36.8)	0 (0.0)
	A1.b	12	10 (83.3)	2 (16.7)	0 (0.0)
	A2.a	19	15 (78.9)	2 (10.5)	2 (10.5)
B. Research	**B1.a**	19	13 (68.4)	3 (15.8)	3 (15.8)
	B2.a	19	14 (73.7)	2 (10.5)	3 (15.8)
	B3	19	12 (63.2)	5 (26.3)	2 (10.5)
	B4	19	2 (10.5)	6 (31.6)	11 (57.9)
C. Progress reports	**C1.a**	18	9 (50.0)	8 (44.4)	1 (5.6)
D. Technical facilities	**D1**	18	15 (83.3)	0 (0.0)	3 (16.7)
	D2	18	9 (50.0)	5 (27.8)	4 (22.2)
	D3	18	7 (38.9)	4 (22.2)	7 (38.9)
	D4	18	1 (5.6)	10 (55.6)	7 (38.9)
E. Ethical implications	**E1**	18	16 (88.9)	1 (5.6)	1 (5.6)
	E2	18	13 (72.2)	2 (11.1)	3 (16.7)
F. Education and training	**F1**	18	Pre-graduate 12 (66.7) Post-graduate 14 (77.8)	1 (5.6)	3 (16.7)
	F2.a	18	13 (72.2)	4 (22.2)	1 (5.6)
G. Citizens	**G1**	18	4 (22.2)	10 (55.6)	4 (22.2)
	G2	18	8 (44.4)	7 (38.9)	3 (16.7)

Italy, Latvia, Lithuania, Luxembourg, The Netherlands, Norway, Poland, Portugal, Slovenia, Spain, Sweden and UK), plus 7 (Austria, Belgium, Bulgaria, Germany, Malta, Romania and Slovakia) that were not present at the Rome meeting, were contacted electronically by the Italian Ministry of Health with a link to the online questionnaire. The cover letter defined public health genomics, using the earlier Bellagio Statement.[3] Respondents were asked to nominate alternatives if they were unable to complete the survey.

Three reminders were made by e-mail. Entries were accepted until November 2015. Respondents were able to attach documents or include hyperlinks to relevant material. Simple tabulations of responses were undertaken, using the number of countries responding as the denominator.

Results

The response rate was 65.5% (19/29 of the CMOs), although one (Ireland) completed only the first two sections of the questionnaire. Table S1 (Supplementary materials) lists the countries that participated in the survey and the date of the questionnaires' submission. Table S2 shows the tabulations of answers by Country for the closed-ended questions.

Table 2 presents responses to each of the 22 survey questions, apart from those relating to public and private funding sources for policies on genomics in healthcare and for research supporting these policies, which are presented in tables 3 and 4, respectively. Results are reported according to the seven sections of the questionnaire.

Section A: policies in place and financial support for policy development

Twelve (63.2%) countries (Austria, Belgium, Estonia, France, Hungary, Italy, Latvia, Norway, Poland, Spain, The Netherlands and the UK) reported having a policy on genomics in healthcare in place, and, out of these countries, 10 (83.3%) (Austria, Belgium, Estonia, France, Hungary, Italy, Poland, Spain, The Netherlands and the UK) documented the presence of specific guidelines (table 2). Fifteen (78.9%) countries (Austria, Belgium, Croatia, Estonia, Finland, France, Hungary, Italy, Malta, Norway, Poland, Slovenia, Spain, The Netherlands and the UK) reported having dedicated funding for development of policies on genomics in healthcare. Of these, all reported that the support was provided by public institutions (table 3). Six countries (40.0%) reported public funding from the Ministry of Research, 14 (93.3%) from the Ministry of Health, 3 (20.0%) from other Ministries and 10 (66.7%) from other public sources. The sums involved ranged from around €50 000/year (four countries, 26.7%) reported a public spending of around €50 000/year (Austria, Finland, Malta, Slovenia), >€200 000/year (6 countries, 40.0%, Belgium, Italy, Poland, Spain, The Netherlands and UK), while respondents from the remaining five countries (33.3%) were unable to give a precise figure.

Of the 15 countries reporting funding for the development of genomics policy in healthcare, five (33.3%, Belgium, Estonia, France, Norway and Spain) reported additional private sources of funding. These were mostly from the pharmaceutical industry (40.0%), private research institutes (60.0%) and other private sources (60.0%). Only two countries (Belgium and Spain) were able to report the amount of private funding, with both documenting an amount of >€200 000/year.

Section B: research in support of policy of genomics in healthcare

Thirteen (68.4%) of the countries (Belgium, Croatia, Estonia, France, Hungary, Italy, Latvia, Norway, Poland, Portugal, Slovenia, Spain and the UK) reported having public research facilities devoted to development of policy or services in genomics. Among these countries, Hungary, Spain and the UK (23.1%) reported having additional private institutions devoted to such research (data not shown).

Fourteen (73.7%) countries (Austria, Belgium, Croatia, Estonia, Finland, France, Italy, Latvia, Norway, Poland, Portugal, Slovenia, Spain and the UK) documented funding from public institutions for research on development of genomics policy in healthcare (table 2). Of these countries, 78.6% identified the Ministry of Health as the source of the public funding, 21.4% the Ministry of Research, 21.4% other ministries and 28.6% other public institutions (table 4). No country reported financial support from private institutions for the development of policies on genomics in healthcare.

Lastly, 12 respondents (63.2%) (Austria, Belgium, Estonia, Finland, France, Hungary, Italy, Latvia, Poland, Spain, The Netherlands and the UK) reported undertaking research projects on policy or service development supported by public funding, while 10.5% (Hungary and The Netherlands) were aware of private funding dedicated to policy research (table 2).

Section C: progress report

Nine countries (50.0%) (Austria, Belgium, Estonia, Italy, Latvia, Norway, Spain, The Netherlands and the UK) reported that national reports on progress in public health genomics were published (table 2). All were addressed to decision-makers, 66.7%

Table 3 Answers on the funding support (and related amount) for the development of genomics in healthcare in the responding countries

Countries reporting any funding support (*N*=15)	N	%
A2.b Public funding	15	100
Public institutions of funding[a]		
Ministry of Research	6	40.0
Ministry of Health	14	93.3
Other Ministries	3	20.0
Other public institutions	10	66.7
A3. Amount of public funding[b]		
£50 000	4	26.7
£50 000–200 000	0	0.0
>£200 000	6	40.0
Not aware	5	33.3
A2.b Private funding	5	33.3
Private institutions of funding[a]		
Pharmaceutical industry	2	40.0
Private research institutions	3	60.0
Other	3	60.0
A4. Amount of private funding[b]		
£50 000	0	0.0
£50 000–200 000	0	0.0
>£200 000	2	13.3
Not aware	13	86.7

[a]Multiple-answer questions. Total is >100% as respondents can select more than one answer.
[b]From the past calendar year, see table 1.

Table 4 Answers on the funding support for the research in policy or services development in genomics in healthcare in the responding countries

Countries reporting any funding support (*N*=14)	*N*	%
B2.b Public funding	14	100.0
Public institutions of funding[a]		
Ministry of Research	3	21.4
Ministry of Health	11	78.6
Other Ministries	3	21.4
Other public institutions	4	28.6
B2.b Private funding	0	0
Private institutions of funding[a]		
Pharmaceutical industry	0	0.0
Private research institutions	0	0.0
Other	0	0.0

[a]Multiple answer questions. Total is >100% as respondents can select more than one answer.

to professionals, 77.8% to researchers, 44.4% to citizens and 33.3% to patients' associations (data not shown). These progress reports were reported as published by universities and government ministries in an equal number of countries. Only in the UK were universities, ministries and other institutions (the UK Genetic Testing Network, UKGTN and the PHG Foundation) listed as publishing reports. A majority of countries reported that progress reports were not regularly updated (data not shown).

Section D: technical facilities and health technology assessment

Fifteen (83.3%) countries (Austria, Belgium, Croatia, Estonia, Finland, France, Hungary, Italy, Malta, Norway, Poland, Slovenia, Spain, The Netherlands and the UK) reported that there were national working groups on the development of policies and/or services related to genomics in the healthcare, of which half worked under the umbrella of the National Ministries of Health. Additionally, 38.9% of the countries (Belgium, France, Italy, Norway, Slovenia, Spain and the UK) reported working groups on the development of genomic policies in healthcare at the regional level (table 2). Nine countries (50%) (Austria, Belgium, Croatia, France, Hungary, Poland, Spain, The Netherlands and the UK) documented the presence of national agencies carrying out Health Technology Assessment (HTA) or horizon scanning on genomic-based technologies. In two of these countries, HTA or horizon scanning was performed by the Ministry of Health (data not shown). Spain was the only country reporting the existence of regional agencies for genomic HTA (table 2).

Section E: ethical and legal implications of policies

Sixteen (88.9%) countries (Austria, Belgium, Croatia, Estonia, Finland, France, Hungary, Italy, Malta, Norway, Poland, Portugal, Slovenia, Spain, The Netherlands and the UK) reported having departments or agencies dealing with ethical issues related to the use of genomics in public health (table 2), with half of these departments being part of the Ministry of Health (data not shown). Thirteen countries (72.2%) (Austria, Belgium, Croatia, Estonia, Finland, France, Malta, Norway, Poland, Portugal, Slovenia, Spain and The Netherlands) were aware of the existence of departments and/or agencies with expertise in engagement in ethical and/or legal matters in genomics (table 2).

Section F: education and training of health professionals

Twelve (66.7%) (Croatia, Estonia, Finland, France, Hungary, Italy, Norway, Poland, Portugal, Slovenia, The Netherlands and the UK) and fourteen (77.8%) countries (Croatia, Estonia, Finland, France, Hungary, Italy, Malta, Norway, Poland, Portugal, Slovenia, Spain, The Netherlands and the UK) reported the presence of pre-graduate and postgraduate, respectively, university courses on genomics in healthcare (table 2).

Thirteen (72.2%) states (Austria, Belgium, Croatia, Estonia, Finland, Hungary, Italy, Malta, Norway, Poland, Slovenia, Spain and the UK) reported having training courses for health professionals on the appropriate use of genetic testing for susceptibility to complex disorders (table 2). All countries reported that these courses were directed to specialized physicians, 53.8% that they were aimed at scientists/researchers, 46.2% at the general practitioners and 38.5% at general health professionals (data not shown).

Section G: citizens

The majority of the responding countries (55.6%) reported a lack of specific information campaigns addressed to citizens (by use of advertisements on billboards, TV or radio, etc.) on genetic tests of susceptibility for complex diseases. Only four countries (Estonia, Poland, Slovenia and Spain) reported having such information campaigns (table 2).

Lastly, eight (44.4%) countries (Austria, Croatia, Estonia, France, Latvia, Slovenia, Spain and The Netherlands) reported that they had adopted a legal framework or professional guidelines on the ethical implications of direct-to-consumer genetic testing (table 2).

Discussion

This paper summarizes the first attempt to survey the policy framework of genomics in healthcare across EU member states. Despite a relatively low response rate of 65.5%, some conclusions can be drawn from the results.

First, few CMOs reported specific guidelines in place for policies on genomics in healthcare in their countries, with 12 reporting having already implemented a policy on genomics in healthcare and 10 reporting the presence of specific guidelines. A detailed examination was undertaken of the documents provided; four

were recent guidelines on PHG (Belgium, France, Italy and UK),[7–11] and the remaining six covered other aspects of genomics and healthcare (e.g. *in vitro* regulation directives, prenatal diagnosis, rare diseases, hereditary tumours and ethical committee).[12–20]

Most CMOs reported that there was financial support available for the development of genomic policies, implying a commitment among some of the countries surveyed to introduce policies where they do not yet exist. This funding was, in most cases, from public sources, typically from the Ministry of Health. A few countries reported additional funding from private institutions, but were unable to support these claims with reference to external organizations or supporting documents. Therefore, with the exception of the United Kingdom (which cites the PHG Foundation and The Genetic Alliance UK as sources of private funding) it appears that there is a relative lack of private funding for the development of policies on genomics in healthcare in the surveyed countries. More progress should be achieved with particular regard to the involvement of private foundations (e.g. the PHG foundation for the UK) or pharma companies while taking into account any bias related to the contribution of for profit companies.

Concerning the presence of research facilities to support the development of policy, these were public in the majority of cases, such as the ''*Inserm: institut thématique multi organisme (ITMO) Santé publique*'' in France, and were also present in countries where dedicated policies are not yet implemented (Croatia and Slovenia). Again, all these research institutions received public funding, mainly from the Ministry of Health.

Half of the responding CMOs reported publication of national progress reports on genomics in healthcare, although few reported that such reports are regularly developed. Again by taking a closer look at the documentation enclosed, those from Belgium and Austria reported on direct-to-consumer genetic tests, those from Italy, Norway, Spain, The Netherlands and UK reported on PHG, while in the remaining countries, the documentation enclosed was not relevant.

Even though the majority of the responding CMOs reported the existence at the national level of working groups dedicated to the development of policies and/or services related to the development of policies on genomics in healthcare, very few (40%) report having equivalent groups at the regional level. Only half of respondents documented the presence of national agencies carrying out HTA or horizon scanning of genomic-based technologies, with only one country (Spain) reporting such agencies at the regional level. This makes Spain the only country reporting the existence of agencies dedicated to HTA or horizon scanning at both the national[21,22] and the regional level (Andalusian region).[23] Some others, like Italy, reported regional agencies (e.g. in the Veneto, Emilia Romagna, and Lombardy regions[24,25]), but none at the national level. Perhaps, dealing with the previous issue the survey can be affected by the different historical approach to HTA of each country.

In contrast, a positive finding of the survey is that most countries appear to have expertise in ethical and legal issues associated with genomic technologies, although respondents submitted few supporting documents to back up the claims made. There are several ethical and legal issues related to the use of genomic-based technology; for example, those pertaining to sharing of personal biological samples in order to further genomic research. The increasing need for such data sharing requires a balance between protecting individuals from foreseeable harms, such as privacy breaches, and allowing the full potential of genomic technologies to be realized.[26]

The survey highlighted how pre- and post-graduate courses on genomics in healthcare are now common.[27] Many include training on the appropriate prescription and adequate interpretation of genetic susceptibility testing for complex disorders.[28] These results are important, as recent evidence suggests that physicians, public health specialists and health professionals are not sufficiently prepared to apply genomic knowledge in prevention or treatment of disease.[29–33] The importance of genomics education among general practitioners and public health specialists has, therefore, been acknowledged at the European level. Policymakers and educational institutions should provide incentives for the interdisciplinary education of healthcare professionals and scientists from the earliest stages of professional development, in addition to specific training for healthcare professionals, bioscientists, ICT professionals and those with expertise in regulatory and social domains to facilitate collaborative development of the tools for genomic medicine across Europe. On that direction, interactions between CMOs and academic institutions through the FEAM and The Association of Schools of Public Health in the European Region (ASPHER) should be promoted and implemented.

The results indicate a lack of educational outreach (through advertisements on billboards, TV or radio, etc.) to general citizens about genomics. This is an issue that must be approached with care, given the potential for misleading claims, but it does suggest that the public may be relatively uninformed about the scope for genetic screening services. It also introduces the problem of a possible *democratic deficit*, which arises when the general population is uninformed about a topic on which legislation is made.[34]

Finally, the results of the survey show that there is a lack of well-defined frameworks (in the form of legal, ethical and professional guidelines) addressed to citizens on the appropriate use of direct-to-consumer genetic tests.[35] In this field, both health literacy and education can play a role in order to prevent the so-called *cascade effect* – defined as the ''*chain of events initiated by an unnecessary test, an unexpected result, or patient or physician anxiety, which results in ill-advised tests or treatments that may cause avoidable adverse effects and/or morbidity*'',[36] which is responsible for unjustified health expenditure, and the advent of *unpatients* – intended as subject sharing a genetic predispositions and waiting for the appearance of any symptoms of illness, while organizing their lives in function of periodic medical examinations and analysis or even feeling sick without any diseases or just developing psychosomatic symptoms.[37] As citizens and patients are increasingly taking advantage of social media and new technologies to participate meaningfully in shared decisions with health professionals about their clinical care, policy makers should establish mechanisms to promote health literacy among European citizens, particularly with regard to direct-to-consumer genetic tests.

The survey is subject to a number of important limitations. First, the response rate was below 70%, as only 19/29 CMOs actually responded to the survey. Second, despite three prompts, we did not receive answers from Cyprus, the Czech Republic, Denmark, Greece, Luxembourg, Sweden, Bulgaria, Germany, Romania or Slovakia, and the lack of some large countries could limit the description of the policy framework of *genomic policies in healthcare* across EU. It is likely, in fact, that these countries have national policies on genomics in place, especially in the case of Central and Northern EU member states, which have participated in relevant projects funded by the EC. Third, in a number of cases, the CMOs were uncertain about the answers (responding with the answer ''Not Aware/Not Certain''), meaning that some activities taking place in university, industry or other organizations could be unknown to the CMOs and we might have underestimated the positive or negative answers from this survey. Also, we are not able to exclude that CMOs asked a second opinion or delegated another subject in order to answer the questions. There raises the doubt if CMOs were the appropriate targets to survey such a very specific topic. However, the CMOs are the most senior advisors on health matters and the importance of their involvement on the topic was emphasized during the CMO meeting. Furthermore, the requirement to search and enclose documents or references to support answers should have stimulated CMOs in undertaking supplementary research on the topic.

Our study did not aim to evaluate the impact of national policy on genomics on health outcomes, which will be an important focal point for future research if meaningful comparisons of policy implementation are to be made across different countries. Recently, a discussion document published by the PHG Foundation proposes a new paradigm that looks beyond PHG as it addresses the changing health needs of populations.[38] The document suggests a new framework for personalised healthcare through which societies might address the problems of health and current healthcare systems, where personalization of healthcare is at the centre. The inclusion of many technologies, alongside genomic technologies, could increase knowledge about individuals and their health and disease, particularly including new biomedical and digital technologies. The development and inclusion of personalised prevention should become a complementary approach to existing paradigms of classical public health practice. In the paper, authors also suggest ways in which the organization of health services and public policy may need to change and adapt to turn these potentials into reality and the role that public health leaders should play in catalyzing these changes.

In conclusion, this survey represents the first attempt to investigate the current state of genomic policy development and implementation among EU member states (plus Norway). The results indicate that some countries have more extensive policies and support structures in place than others. Absence of funding for policy development in several countries represents a challenge that should be urgently addressed, particularly by exploring the possibility of involving the private sector in contributing to funding. Additionally, even though the vast majority of the respondents reported having working groups on genomics, there is a lack of structured information campaigns for citizens on genomics in general and direct-to-consumer genetic testing in particular.

The results of our survey suggest a need for a co-ordinated effort to foster the development and further harmonization of dedicated policies across the EU in order to integrate genomics policies into existing health systems in a responsible manner. Introducing a common policy framework on PHG at the EU level could represent one of the drivers needed to manage a future with increasingly personalized healthcare and a shift in the use of genomic approaches from disease treatment to prevention.

Supplementary data

Supplementary data are available at *EURPUB* online.

Acknowledgments

The authors would like to thank Martin Mckee for the extensive revision of the manuscript, and Felice Iossa for the technical support in implementing the online survey. Authors thank the Federation of European Academies of Medicine (FEAM) for the precious support offered during the pilot survey which is part of the final version.

Funding

The work is funded by the Center for Disease Control (Centro Nazionale per il Controllo delle Malattie CCM) of the Italian Ministry of Health within the project entitled ''The economic impact of genetic testing on the National Health Service: evaluation of diagnostic care pathways estimates of cost-effectiveness and cost-utility and investigation of health policies at European level'', grant from Italian Ministry of Health (Project reference n. (CUP): B85J11000540001); the Personalized Prevention of Chronic DIsesase (PRECeDI) project (Marie Skłodowska-Curie Research and Innovation Staff Exchange – RISE, Contract number: 645740); the working group of Public Health Genomics of the Italian Society of Hygiene and Preventive Medicine (SItI).

Conflicts of interest: None declared.

Key points

- This survey represents the first attempt to investigate the current state of genomic policy development and implementation among EU member states. Some countries have more extensive policies and support structures in place than others.
- Absence of funding for policy development in several countries represents a challenge that should be urgently addressed, particularly by exploring the possibility of involving the private sector in contributing to funding.
- The importance of implementing genomics education among general practitioners and public health specialists at the European level has to be highlighted.
- There is a lack of structured information campaigns for citizens on genomics in general and direct-to-consumer genetic testing in particular.
- The results suggest a need for a co-ordinated effort to foster the development and further harmonization of dedicated policies across the EU in order to integrate genomics policies into existing health systems in a responsible manner.

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