



Beyond One Million Genomes

D6.7

Guiding principles and best practices examples for mirror groups

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B1MG

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1. Executive Summary

Mirror groups are a national reflection of the working groups set up by the 1+MG Initiative. Due to the differences among countries, both in terms of research and innovation and health systems governance and also based on their approaches to the 1+MG initiative, mirror groups are set up in different configurations.

As a first action, we designed and circulated a survey in 2020 in order to map the configurations of the NMGs and have a first vision on how countries were establishing their NMG by taking the peculiarities of the different National Health Systems and governance into account. This mapping helped us to know how and to what extent NMGs connect with their national initiatives. This survey was complemented with bilateral meetings with some countries to gain a deeper knowledge about the structure and operation of NMGs in those countries and its implementation at the national level.

Because of the important role of National Mirror Groups in preparing the country for implementation of 1+MG on the practical and political level, it is essential to monitor their status and performance to come up with recommendations and best practices to share among the set of NMGs.

To this aim, the following actions have been carried out:

- The development of an initial factsheet called 'National Mirror Groups at a Glance' to help countries clarify the mission, role, tasks and structure of NMGs in the initiative for the time being.
- Bilateral meetings have been held with some countries to gain knowledge about the structure and operation of NMGs in those countries and its implementation at the national level.
- Two surveys have been circulated among the participating Member States and the Observer Countries of the initiative to analyse the evolution of the different existing mirror groups assessing its structure, composition, governance, and operating modes as well as whether they were correlated with their national structures.

After analysing the results, it has been found that in most of the countries the WG1 representative is the main figure that coordinates the NMGs, that **47,37%** of the countries consider that their NMGs are 'Operational', and that the majority of the countries consider that there is engagement between their NMGs and the initiative. It seems that the majority matched their configuration with "Small countries with National Genomics Strategy' model" or "Countries starting to set up their NMGs' model". Two countries identified "Big countries with National Health Service System" as their current status. Besides, the composition of the NMGs is quite heterogeneous among countries. Regarding the representation of stakeholders, it should be noted that most of the countries have a high level of representation of the research and university communities and not so much neither from the clinical nor the IT/Data communities.

By comparing the results from the two surveys that have been circulated, between November, 2020 - February, 2022, we have noted some improvements in the number of operational NMGs, the establishment of the governance structure, the level of activity of the NMGs, the engagement between NMGs and the initiative, the definition of NMG composition, the number of members involved and the signature of some "Terms of references" by some countries.



To achieve the goals regarding NMGs set up in the roadmap of the initiative¹, it would be recommendable that all NMGs have a higher level of engagement with the initiative and that they are better aligned with national initiatives and countries adding more stakeholders related with patient organisations, industry and clinical communities.

This data has enabled the setting up of some guiding principles and the identification of a set of best practices for the good set-up, running and coordination of mirror groups.

¹1+Million Genomes Roadmap 2020-2022 – adopted on 4 February 2020 by the signatories of the Declaration:
<https://digital-strategy.ec.europa.eu/en/library/roadmap-1million-genomes-initiative-now-clearly-illustrated-new-brochure>



2. Contribution towards project objectives

With this deliverable, the project has reached or the deliverable has contributed to the following objectives/key results:

	Key Result No and description	Contributed
Objective 1 Engage local, regional, national and European stakeholders to define the requirements for cross-border access to genomics and personalised medicine data	1. B1MG assembles key local, national, European and global actors in the field of Personalised Medicine within a B1MG Stakeholder Coordination Group (WP1) by M6.	No
	2. B1MG drives broad engagement around European access to personalised medicine data via the B1MG Stakeholder Coordination Portal (WP1) following the B1MG Communication Strategy (WP6) by M12.	No
	3. B1MG establishes awareness and dialogue with a broad set of societal actors via a continuously monitored and refined communications strategy (WP1, WP6) by M12, M18, M24 & M30.	Yes
	4. The open B1MG Summit (M18) engages and ensures that the views of all relevant stakeholders are captured in B1MG requirements and guidelines (WP1, WP6).	Yes
Objective 2 Translate requirements for data quality, standards, technical infrastructure, and ELSI into technical specifications and implementation guidelines that captures European best practice	Legal & Ethical Key Results	
	1. Establish relevant best practice in ethics of cross-border access to genome and phenotypic data (WP2) by M36	No
	2. Analysis of legal framework and development of common minimum standard (WP2) by M36.	No
	3. Cross-border Data Access and Use Governance Toolkit Framework (WP2) by M36.	No
	Technical Key Results	
	4. Quality metrics for sequencing (WP3) by M12.	No
	5. Best practices for Next Generation Sequencing (WP3) by M24.	No
	6. Phenotypic and clinical metadata framework (WP3) by M12, M24 & M36.	No
	7. Best practices in sharing and linking phenotypic and genetic data (WP3) by M12 & M24.	No
	8. Data analysis challenge (WP3) by M36.	No
	Infrastructure Key Results	
	9. Secure cross-border data access roadmap (WP4) by M12 & M36.	No
	10. Secure cross-border data access demonstrator (WP4) by M24.	No



Objective 3 Drive adoption and support long-term operation by organisations at local, regional, national and European level by providing guidance on phased development (via the B1MG maturity level model), and a methodology for economic evaluation	1. The B1MG maturity level model (WP5) by M24.	No
	2. Roadmap and guidance tools for countries for effective implementation of Personalised Medicine (WP5) by M36.	Yes
	3. Economic evaluation models for Personalised Medicine and case studies (WP5) by M30.	No
	4. Guidance principles for national mirror groups and cross-border Personalised Medicine governance (WP6) by M30.	Yes
	5. Long-term sustainability design and funding routes for cross-border Personalised Medicine delivery (WP6) by M34.	Yes

3. Methods

For the elaboration of this deliverable (Guiding principles and best practices examples for mirror groups) we started from the first survey and its results.

In accordance with the results obtained, we prepared a second survey where we qualified and added some other questions in order to complement it and have a full vision of the situation of NMGs (see section 9.1). The survey was circulated to the person in charge of each NMG in February 2022.

4. Description of work accomplished

4.1 Second National Mirror Groups Survey

4.1.1 Profile and contacts

This section aims to collect information about the main people involved in each NMG and their contacts for further details if needed.

- Representative of WG1.
- NMGs Coordinator.
- National Contact Point of NMGs.
- Different or additional figures for NMGs.

4.1.2 National Health Genomics Plan

This section aims to know the development and the scope of policies devoted to the implementation of genomics in each NMG country.



- Establishment of a National Health Genomics Plan in the country.
- Webpage of the Plan.
- Contact person for the Plan.
- Short explanation of scope and size of the Plan.
- National Health Genomics Plan in alignment with the 1+MG initiative

4.1.3 National 1+MG Roadmap

This section aims to know the development of policies devoted to the implementation of 1+MG supporting policies in each NMG country.

- Establishment of a roadmap related to the 1+MG initiative in the country.
- How the roadmap is implemented in the country.

4.1.4 National Mirror Groups composition and functioning

An important section of the survey as it comprises all of the functional aspects of the NMG. Here, we address the actual developmental stage of each NMG, the member composition (number, working group, stakeholders involvement), the establishment of relevant processes (expert nomination, communication channels...) and/or the governance structure, activities and financial support at national level, and whether or not there exists a "Terms of reference" from the government.

- Stage in establishing a 1+MG National Mirror Group in the country.
 - No tangible activities yet (No expert nominations for the NMGs yet)
 - Planning/preparing (Not all NMGs exist but expert nominations begin)
 - Constructing/starting up (Most experts nominated and governance structure beginning to be implemented)
 - Operational (NMGs filled with nominated experts and an operational governance structure established)
 - Short explanation of the stage
- Composition of NMGs.
- Organisational models of NMGs
 - 'Small countries with National Genomics Strategy' model
 - 'Big countries with National Health Service System' model
 - Countries starting to set up their NMGs' model
 - Other organisational model Short explanation
- Expert nomination process to join the NMGs.
- Governance structure in the NMGs.
- "Terms of reference" from the government.
- Communication process with and among NMGs.
- Activities organised at national level with the NMGs.
- Financial support.

4.1.5 NMGs links to the 1+MG Initiative

In this section, we assess if the NMGs considered that there is a proper link with the 1+MG initiative to implement their actions and recommendations at the national level.

- How active NMGs members are in the Initiative.



- There are sufficient links between NMGs and the European Initiative and how they would be further involved/engaged.

4.1.6 NMGs composition

Along with this survey, countries in which experts had already been nominated to form part of the NMGs were asked to complete a file with the following information on the nominated experts:

- Working Group of the initiative to which it belongs.
- Role: coordinator/expert.
- Type of actor (stakeholder):
 - Ministry/Agency/Executive/Policy Maker.
 - Research/University.
 - Clinical communities.
 - IT/Data communities.
 - Scientific communities.
 - Policy advisory groups.
 - Industry/Private sector.
 - ELSI.
 - Funding Agencies.
 - Patient organisations.
- Institution.
- Name.
- Position.
- Gender.
- Region of the country (if applicable or relevant).
- Contact.

5. Results

All these results have been periodically communicated to the Coordination Group of the initiative and in the various meetings held within the B1MG Project and the 1 + MG initiative.

NOTE: These results show a picture of the state of the NMGs at the time when the responses were submitted. It is possible that during data collection the configuration of the NMGs in the different countries has changed or evolved.

NOTE: There are some countries that responded to the first survey but did not answer the second one. Other countries only responded to the second survey so we have no previous data. In these cases, we cannot have a proper reflection of their evolution.



5.1. Survey Results

Of the 24 signatory countries, 19² countries have responded to the second survey, of which 16³ countries have sent the composition of their NMGs. In the Table 1, more detail about the responses received:

Table 1. Responses to the two surveys

Country	Acronym	1 st survey	2 nd survey
Austria	AT	NO	NO
Belgium	BE	YES	YES
Bulgaria	BG	YES	NO
Croatia	HR	YES	NO
Cyprus	CY	YES	NO
Czech Republic	CZ	YES	YES
Denmark	DK	YES	YES
Estonia	EE	NO	YES
Finland	FI	YES	YES
France	FR	NO	NO
Germany	DE	YES	YES
Greece	GR	NO	NO
Hungary	HU	YES	YES
Ireland	IR	NO	YES
Italy	IT	YES	YES
Latvia	LV	YES	YES
Lithuania	LI	YES	YES
Luxembourg	LU	YES	YES
Malta	MT	YES	YES
Netherlands	NL	YES	YES

²The countries that responded to this second survey were: BG, CZ, DK, EE, FI, DE, HU, IR, IT, LV, LT, LU, MT, NL, NO, PL, PT, ES and SE.

³The countries that submitted the composition of their NMGs were: CZ, DK, EE, FI, DE, HU, IR, IT, LV, LT, LU, NL, NO, PT, ES and SE.



Norway	NO	YES	YES
Poland	PL	NO	YES
Portugal	PT	YES	YES
Slovenia	SI	NO	NO
Spain	ES	YES	YES
Sweden	SE	NO	YES
Switzerland	CH	NO	NO
UK	UK	YES	NO
Totals		19	19

The results of the second survey are collected in the following tables:

Table 2. Results from the section “Profile and contacts” of the second survey

Profile and contacts	Yes	No	Same WG1 representative
NMGs Coordinator	4/19 = 21,05%	1/19 = 5,26%	14/19 = 73,68%
NCP of NMGs	10/19= 52,63%	1/19= 5,26%	8/19= 42,11%
Different or additional figure	4/19= 21,05%	15/19 = 78,95%	-



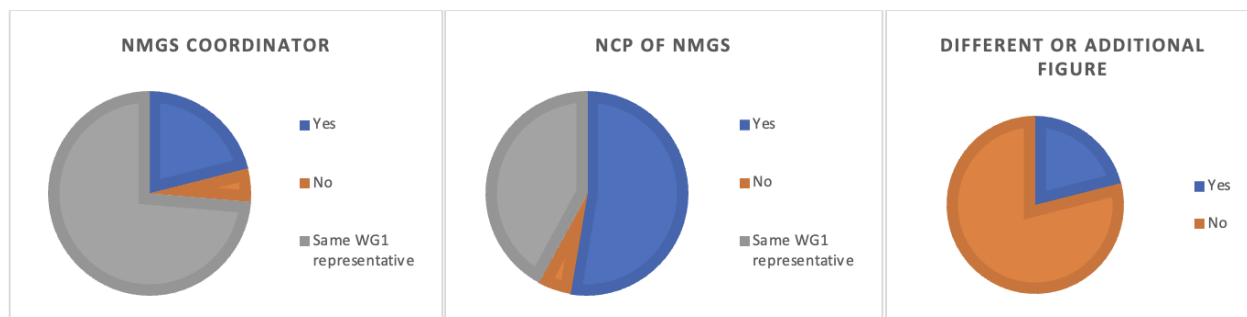


Figure 1. Results from the section “Profile and contacts” of the second survey

Table 3. Results from the section “National Genomics Plan” and “National 1+MG Roadmap” of the second survey

National Health Genomics Plan (NHGP) and 1+MG Roadmap	Yes	No
Have National Health Genomics Plan	9/19 = 47,37%	10/19 = 52,63%
Have National 1+MG Roadmap	8/19 = 42,11%	11/19 = 57,89%
Alignment : NHGP- National 1+MG Roadmap	6/9 = 66,67%	3/9 = 55,56%

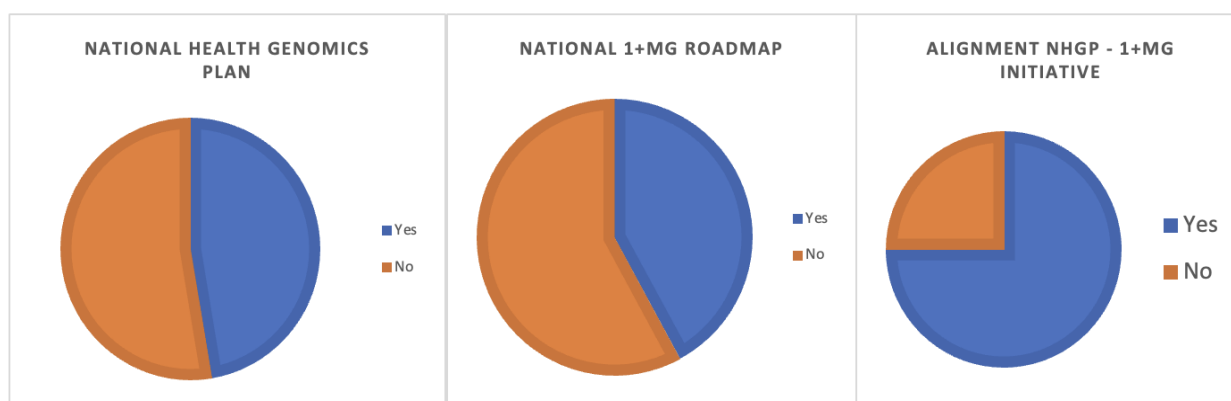


Figure 2. Results from the section “National Genomics Plan” and “National 1+MG Roadmap” of the second survey.

Table 4. Results from the section “National Mirror Groups Composition and Functioning” of the second survey

National Mirror Groups composition and functioning	No tangible activities yet	Planning/ preparing	Constructing/ starting up	Operational
Stage in establishing NMGs	1/19 5,25%	4/19= 21,05%	5/19= 26,32%	9/19= 47,37%
	Yes		No	
Expert nomination process	12/19 = 63,16%		7/19= 36,84%	
Communication process ⁴	12/18= 66,67%		6/18 = 33,33%	
Governance structure	12/19 = 63,16%		7/19= 36,84%	
Activities organized at national level	12/19 = 63,16%		7/19= 36,84%	
Funding or specific assignment	6/19 = 31,58%		13/19 = 68,42%	
Terms of reference	4/19 = 21,05%		15/19 = 78,95%	

⁴This answer is over 18 answers because MT did not answer this question.

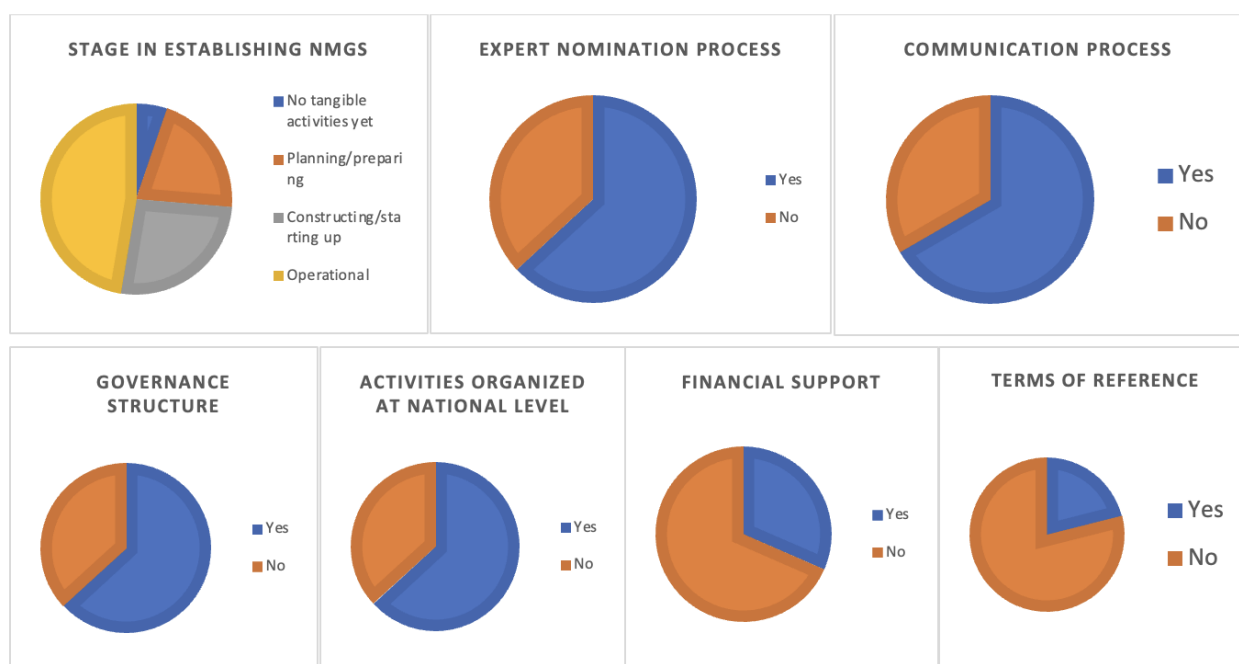


Figure 3. Results from the section “National Mirror Groups Composition and Functioning” of the second survey

Table 5. NMG’s organisational model results

NMGs’ organisational model	Small countries with National Genomics Strategy’ model ⁵	Countries starting to set up their NMGS’ model ⁶	Big countries with National Health Service System’ model ⁷	Other organization al model
Organisational model of the NMGS	6/19 =31,58%	7/19 = 36,84%	2/19 = 10,53%	4/19 = 21,05%

⁵Small countries with National Genomics Strategy’ model: because of the size of the country and the internal organisation models, they have created a kind of ‘core group’ with people involved in ministry, experts, industry and all the stakeholder representation. They also have a more operational group, like a subgroup of this ‘core group’. And finally have an open forum of stakeholders to exchange information, like an open window to who wants to join the initiative.

⁶Countries starting to set up their NMGS’ model: in these countries there is only one NMG composed of national representatives for the 11 WGs of the initiative.

⁷Big countries with National Health Service System’ model: these countries have established NMGS for each WG of the initiative. These 11 NMGS are coordinated by the national representative of each WG in the initiative and each group is composed of between 5-7 experts.

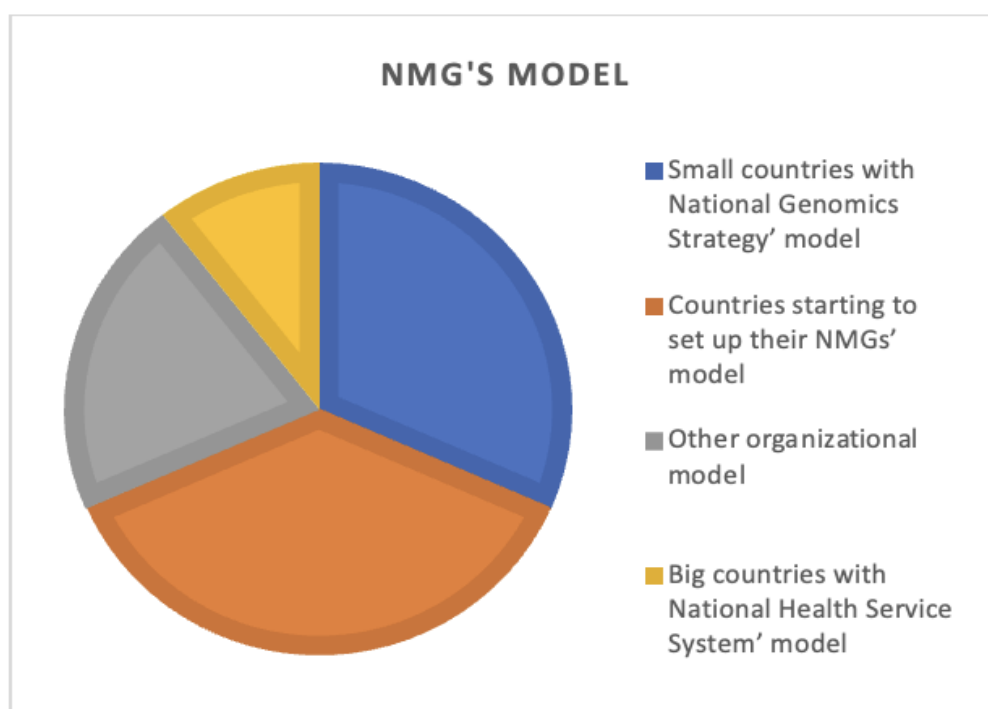


Figure 4. NMG's organisational model results

Table 6. Results from the section "NMG links to the 1+MG Initiative" of the second survey

NMGs links to the 1MG Initiative	Value 1	Value 2	Value 3	Value 4	Value 5
How active are NMGs members in the initiative	2/19 = 10,53%	0/19 = 0%	5/19 = 26,32%	7/19 = 36,84%	5/19 = 26,32%
	Yes		No		
Engagement between NMGs and initiative	15/19 = 78,95%		4/19 = 21,05%		

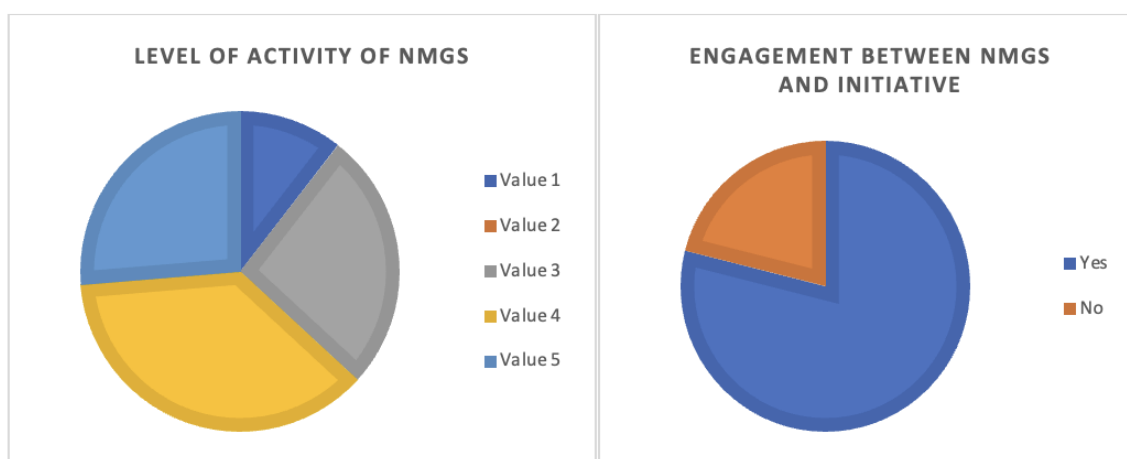


Figure 5. Results from the section “NMG links to the 1+MG Initiative” of the second survey

5.2. Composition Results

To date, 16⁸ countries have submitted their composition of experts on the NMGs. Below we analyse the most relevant results:

5.2.1. Representation in the initiative's Working Groups (WGs) and Size of NMGs

Only **6** (FI, DE, IT, ES, EE, LV) of the 16 **countries have experts in all the initiative's 12 WGs**.

The **most common case** is that **NMGs composition includes between 10-20 experts**. There are two countries whose NMGs are more numerous with 100 experts approximately involved (IT, ES), as for each WG there is a NMG with several experts in it.

5.2.2. Type of Stakeholders

Regarding stakeholder representation, **the compositions are quite heterogeneous among countries**. Though the most represented group in NMGs in most countries are experts from ‘**Research/University**’.

⁸The countries that submitted the composition of their NMGs were: CZ, DK, EE, FI, DE, HU, IR, IT, LV, LT, LU, NL, NO, PT, ES and SE.

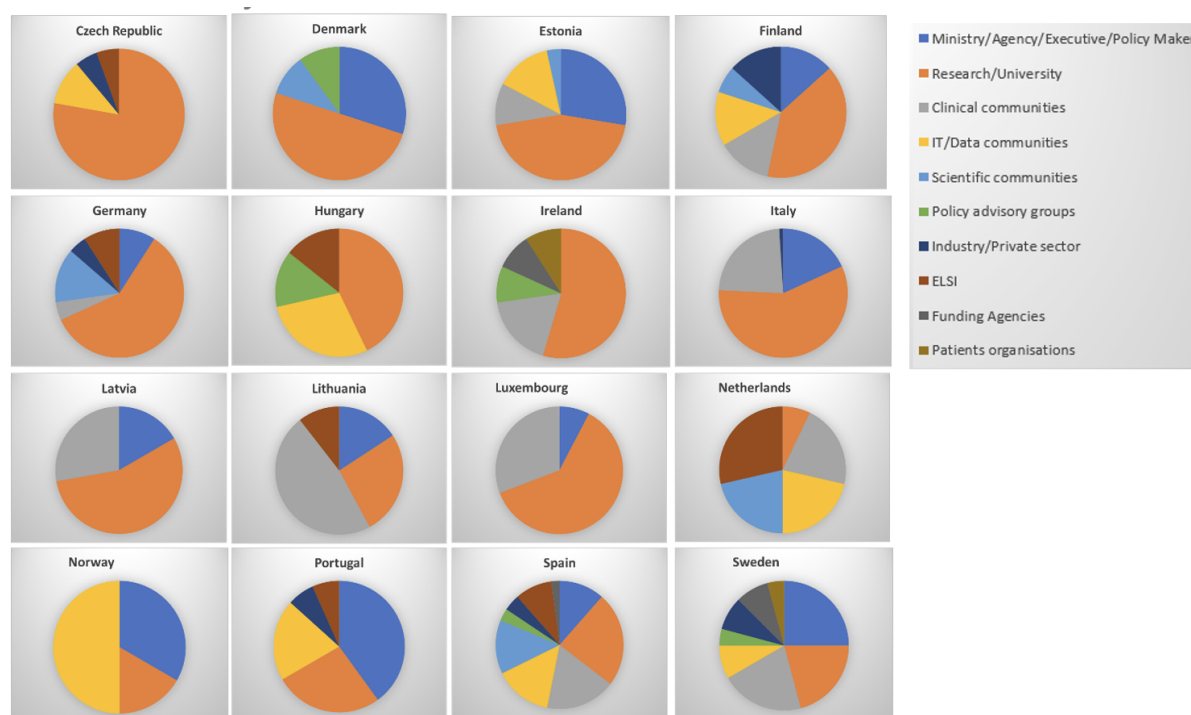


Figure 6. Stakeholder composition of each NMG

Three countries differ on this:

- **NO**, where the most represented group is 'IT/Data communities' (50%).
- **LT**, where the most represented groups are 'Clinical Communities' (47.37%)
- **PT**, where the most represented group is 'Ministry/Agency/Executive/Policy Maker' (40%).
- Other countries such as NT, SE and ES distributed their experts in a variety of stakeholders.
- Only two countries (SE, IR) have representatives of '**Patient Organizations**' in its NMGs.
- '**Funding Agencies**' are represented in only 3 countries (IR, ES, SE).
- There is some representation of the '**Industry/Private Sector**' in the NMGs in half of the countries (BG, CZ, FI, DE, IT, PT, ES, SE).

No country has representatives of all types of stakeholders on its NMGs.

6. Analysis

6.1. Profile and contacts

In most of the countries, the WG1 representative is the main figure that coordinates the NMGs. However, only one country (EE) declared that they still do not have an NMG coordinator. Those countries that had no NMG coordinator in the first survey declared to have assigned one.

Similarly, NMGs have established their NCP although almost half of the respondents assigned this role to the WG1 representative, as occurred in the first survey.

Regarding additional figures, they have been reduced as the NMG have established their coordinator, NCP and composition. Just one country has a well defined additional figure, Finland. They have an Expert Group on Genomic Medicine, hosted by THL, which advises on the clinical use of genomics in the country. The Group works in collaboration with the NMG.

6.2. National Health Genomics Plan and National 1+MG Roadmap

In between surveys, a number of National Genomics Plans have been developed that are aligned with the 1+MG Roadmap. It should be noted that Lithuania, Czech Republic and Luxembourg replied that they do not have a Genomics Plan but do have a policy related to rare diseases.

6.3. National Mirror Groups composition and functioning

6.3.1 Stage and organisational model

In the previous survey, most of the countries were 'Planning/Preparing' or 'Constructing/Starting up' their NMGs and only 22.22% considered that their NMGs were 'Operational'. Now, the results from the second survey have confirmed that almost half of the NMGs (47,37%) are "Operational". However, some countries that chose this option have not established their governance nor expert nomination process. Therefore, although it seems that the number of countries at operational level has improved, it has not reached the percentage (75%) recommended by the end of 2021.

According to the configurations defined in the first survey, respondents were asked to choose the best which fit with their actual NMG structure. It seems that the majority matched with "Small countries with National Genomics Strategy' model" or "Countries starting to set up their NMGs' model". Two countries, ES and IT, identified with "Big countries with National Health Service System". It is observed that this coincides with the fact that these countries are bigger than others and have a National Health Service System, so it is possible that they need more experts to represent the total population and communities.

On the other side, PT, EE and NL have "Other organisational model".



- **EE:** Our model is similar to the “Small countries with National Genomics Strategy” model, although the representation from the industry would be included only where and when needed.
- **PT:** Selected experts in all areas 1+MG WG areas were nominated by the Ministry of Health to form a commission for the National strategy for Genomic Medicine (PT_MedGen) and coordinate working groups with additional experts chosen by the commission, with whom they are in regular contact.
- **NL:** The NMG is not formalised yet. Currently we have a dedicated team of experts that is active in 1+MG WGs and, in addition, representation from relevant stakeholders.

6.3.2. Communication and governance

The number of countries with defined governance has increased. It should be noted the governance established by:

- **FI:** The National Coordinator chairs the meetings, which have a formal agenda, minutes and to-do lists. The Secretariat for the Finnish implementation (FI+MG) at the Ministry manages the daily administration. All twelve 1+MG Working Groups have a Finnish representative (and often also an alternate). The role of a representative is well understood and there are regular coordination and strategy meetings of the NMG, called the National Coordination Group (FI+MG CG). The NMG is fully functional and supported by the Secretariat at the Ministry (FI+MG SEC). Finland is helped by the fact that Finland contributes to the 1+MG through the leadership in Working Groups 5, 7 and 11 as well as by involvement in the B1MG support action.
- **PT:** The PT_MedGen Commission was nominated by the Ministry of Health and is led by INSA. The nominated experts coordinate working groups overlapping mostly with the 1+MG initiative WGs, and participate in the 1+MG WGs. There is a consultant group to this commission formed by relevant stakeholders (e.g. Health Directorate, regulatory agencies, funding agencies, patient associations) who provide advice and input regarding documents produced by the PT_MedGen Commission.
- **ES:** After the signature of the declaration by Spain, two national coordinators of the NMGs and an NCP were appointed to manage the activity of the NMGs. The NMGs are organised through 12 groups (coinciding with the 12 working groups of the initiative) in which there is a NMG leader who is in charge of coordinating and managing the work of that particular NMGs experts. Additionally, the Carlos III Health Institute, representative entity in this initiative, belongs both to the Science and Health ministries, and its main role is to promote R&D in the Spanish Health Ecosystem. For that, the experts that constitute the NMGs belong to institutions of high relevance in the national health research ecosystem and linked to Carlos III Health Institute such as HRI, Universities, national centres for cancer and sequencing, etc."

Together with the governance, communication procedures have also increased among countries.

6.3.3. Expert process nomination

Expert nomination processes have been defined. It should be noted that in most countries a Ministry is involved to approve the adhesion of a member, this Ministry is generally the Ministry of Health. Those countries with a larger number of components in their NMGs that respond to the "Big countries with National Health Service System" model do not involve any Ministries, but the process is initiated by the coordinators who nominate the candidates and the NCP approves



their adhesion. This flexibility in the process could have contributed to the big sizes of these NMGs.

6.3.4. Terms of reference

An additional question was added to this second survey related to having a “Terms of Reference”. Some countries have responded affirmatively to this question:

- **FI:** The steering group of the Ministry approved the project note including the role, functions and the composition of the Coordination Group (the National Mirror Group). The FI+MG Secretariat updates regularly the background note on the 1+MG (2-pager), which defines the composition and tasks of the Finland-NMG. The NMG agrees annually on its work plan.
- **PT:** It has a mandate to define the National Strategy for Genomic Medicine and design and implement the terms for contribution to the 1+MG initiative.
- **IT:** The Coordinators of each Group lead the operations, through a strong collaboration with the other NMGs, the Ministry of Health and the other stakeholders involved.
- **NO:** The government (Ministry of Health) has appointed the Norwegian Directorate of Health the task to follow up on 1+MG.

6.3.5. NMGs composition

In general, the composition of the NMGs is quite heterogeneous among all the countries. It seems that the composition of NMGs has remained stable, although some countries have lost or gained members.

Most of the countries have a high representation of the research and university communities and not so much of neither the clinical nor the IT/data community. There is also insufficient representation from patient organisations. The industry is only represented in half of the countries. 4 NMGs lack representation from the Ministry/Agency/Executive/Policy Maker. Furthermore, no country has representation of all types of stakeholders in its NMGs.

In addition, the structure of some NMGs have changed not only in the percentage but also in the composition. It is observed that some entities that were previously part of the NMGs according to the results from the first survey were no longer involved.

As a summary, we should note that:

- The countries with a more heterogeneous NMG composition in terms of stakeholders are: ES and SE.
- The countries with more stakeholder participation are: ES and IT. Both were considered as a “Big countries with National Health Service System” model. Each NMG-WG in the initiative is coordinated by the national representative and each group is composed of between 5-7 experts (approx.)”
- 6 countries have NMG representation of all 1+MG WGs: EE, FI, DE, IT, LV and ES.
- The countries that have demonstrated a more stable composition of their NMGs are CZ, FI and DE.
- LI and ES have the same type of stakeholders, but the percentage has changed in between surveys.



- HU, PT and LV are the countries with more differences between NMG composition in comparing the results from the first and the second survey, they have gained/lost some type of the stakeholders involved.

6.4. NMGs links to the 1+MG Initiative

Most of the NMGs (78,95%) considered that there is an important level of engagement between their NMGs and the initiative. A number that has increased in comparison with the first survey (57,89%). The level of activity of the NMGs have also increased.

Nonetheless, the percentages of activities organised at national level and the funding support are mostly similar to the first survey results. Regarding financial support, more than a half of the NMGs (68,42%) have declared that they receive some financial support but it usually consists of in-kind contributions.

7. Conclusions

The following data have increased or improved in comparison to the first survey results:

- Number of operational NMGs from 22,22% to 47,37%
- Establishment of the governance structure
- Level of activity of the NMGs
- Engagement between NMGs and the initiative
- Some countries have signed a “Terms of reference”
- Better definition of the compositions of NMGs
- Some countries have grown their NMGs in terms of members involved.

Finland is the only country which responded affirmatively to all of the survey questions. It could be an example of best practices within the NMGs. According to this criteria, other exemplar countries could be IT, ESP and PT. These four countries have achieved to establish their NMG at operational level, with a well-define governance, expert nomination process, regular communication activities among the NMGs and inside each NMG-WG, a high representation from different stakeholders and participation in almost all the WGs, important alignment between the 1+MG initiative and national policies. In addition, IT, PT and FI have signed “Terms of reference” to strengthen the engagement between the European and the national level activities, and the management of the NMGs.

Some countries have taken advantage from the survey to make some suggestions:

- **BU.** Formalisation and funding of the activities of NMG could improve involvement of the members. All of them are at a high level at their competence and engaged with a lot of



activities. Working just as volunteers, does not bring necessary commitment to most of them.

- **CZ.** 1) Many members are too busy with local sequencing projects (intra- or inter-institutional) and other research work, which often makes them unable to attend the meetings. Therefore, it has been recently quite demanding to catch up with the progress of all working groups and get a general overview of the European Initiatives' activities. 2) One can get easily lost in the amount of emails, pieces of information and tasks sent from various European genomic initiatives. It would be valuable to have one regularly-updated online dashboard to see what is happening now, what is needed and what deadlines and meetings are approaching. One common dashboard for 1+MG, B1MG as well as genomic expert group under European Commission, would be the best.
- **FI.** All the 1+MG WGs should have a concrete, written annual work plan as well as a longer-term mission statement. They could be time-limited to carry out a defined task instead of continuous, with activity invented on the way. The activity level of EU-level WGs varies as most of their members are not paid for their contribution (as is the case in Finland). The output of the Work Packages of B1MG provides an example how funding dramatically changes effectiveness thanks to people paid for the task. The work of active members of the WGs needs to be acknowledged clearly. The activity level and the way of working of the Working Group influences the engagement and experience of the Finnish representatives. The mutual mentoring of the Working Group leaders should include not only the issues on the substance but also the dynamics of the international groups.
- **NL.** Once we receive funding for a national genome program, formalise a NMG, they can dedicate more time. The Dutch Mirror Group awaits formalisation with a clear mandate from our Government. This will help to strengthen the link to the 1+MG initiative. The Netherlands has a strong background in genomics and health, and has established strong international relations at all levels of the 1+MG initiative. Already, several colleagues in the NMG and wider Dutch genomics community are actively engaged in 1+MG Coordination Group, Working Groups and B1MG Work Packages.
- **ES.** Although in Spain there is a good engagement of the NMGs with the initiative, it is true that it depends a lot on the WG. For example, given that WG11 has barely met in 2021, the NMG related to WG11 has been able to make little progress, as have the NMGs related to WG7 and WG12. However, NMG2 (related to WG2) does work steadily and with its bimonthly meetings.

8. Recommendations

After analysing the overall of the results from the first and the second surveys, we can offer some recommendations:

- **Profiles and contacts for the management of NMGs:** As the NMGs have established their profiles and contacts, they have started to work efficiently in the implementation of the actions to be taken in the 1+MG context. Therefore, it is evident that it is necessary to define and clarify the profiles and contacts for the management of NMGs.



- **Stage in establishing NMGs:** Although the majority of the countries have responded in this second survey to be at “operational” level, some of them have not yet established their governance, expert nomination process, communication procedures... Therefore, the specific requirements should be defined to assess objectively if a country has truly achieved the operational status.
- **Establishment of NMGs:** It is still necessary to establish minimum rules for the establishment of NMGs in terms of structure and operation, which were flexible enough to adapt to the nature of the country and the NHS, so that all the NMGs of the countries had the capacity to interoperate, with each other and with the initiative, in the most operational way possible.
- **Stakeholders’ representation:** Countries should be encouraged to:
 - Enrich their NMGs to have as much stakeholder representation as possible.
 - The inclusion of patient organisations and industry representatives in the NMGs.
 - Balance the participation of scientific communities and clinical communities so that all the advances of the initiative also reach the end user who will be healthcare providers.
 - To have on board a policy body is relevant to pave the way for the 1+MG initiative to achieve their mission: to enable secure access to genomics and the corresponding clinical data across Europe for better research, personalised healthcare and health policy making.
 - Not all the NMGs have representation in all of the WGs, this is a key issue because of the permanent feedback and coordination that should have in the two ways: 1) for the 1+MG WGs to have the opinion and perspective from the national level experts, 2) for the countries to have knowledge about the plan of the 1+MG Special Group in the different working groups and proceed to evaluate the implementation at national level.
- **Funding or specific assignment:** Ways should be sought through which the work of the NMGs is financed by the countries, either through the financing of personnel in charge of their management, or through bonuses or incentives that increase the engagement of the experts with the NMGs and the initiative.
- **Engagement between NMGs and the initiative:** it is necessary that there is clear coordination between the representative within the Commission Special Group of the initiative and the NMG representative or coordinator. This engagement is fundamental in this initiative because of its bottom-up approach.
- **Alignment with national initiatives:** It is necessary that all NMGs have an important engagement with the initiative and that in turn they can be aligned with national initiatives so that the work of the NMGs is as efficient and constructive as possible.
- **Additional entities:** although it is not a key issue, could be a good way to align other constituted groups involved in similar projects/programme/activities at national level, they could act as an external board if they were not interested in participating as individual members in a specific NMG-WG.




- **Expert nomination process:** we have identified that in the majority of the countries, the Ministry of Health is directly involved in the approval of members of the NMGs. Only two countries present a “big size” model. These countries follow a different expert nomination process, the coordinator of each NMG-WG nominates or approves the adhesion of new members. Therefore, each country should balance if they prefer a more flexible procedure placing the responsibility to the NMG coordinators or a more controlled procedure which could be slower because of the need for final approval from the Ministry.
- **Communication and governance:** regular fixed meetings independent from the WG-Special Group meetings should be taken place in order to boost the activity of the NMG-WG, contributing in this way to the bottom-up approach. Additionally, this would contribute to creating a continuous conversation between the coordinator and the rest of the NMG-WGs members. With this second aim, we should avoid the feeling of the members being lost in the amount of emails, pieces of information and tasks sent from various European genomic initiatives.
- **A “Terms of reference”** could be a good starting point to define the tasks and activities of NMGs and strengthen the collaboration between the Ministries and the other stakeholders involved.
- **NMG Plan:** On the basis of Finland’s experience, it may constitute a useful tool to delineate the mission of the NMG, their tasks and the achievements to accomplish in a short, medium or long-term according to what it is expected from this country from the 1+MG roadmap.



9. Annexes

9.1. National Mirror Groups – Second Survey



Beyond One Million Genomes

Questions regarding the development and organization of National Mirror Groups (NMGs) in the framework of the 1+MG initiative - Second Round

***Mandatory answers**

Profile and Contacts

1. Country:*

2. Representatives in WG1:*

Name	Affiliation	e-mail address

3. NMGs Coordinator:*

Name	Affiliation	e-mail address


NOTE: The NMGs Coordinator is the person in charge of NMGs of your country.

4. National Contact Point of NMGs:*


Name	Affiliation	e-mail address

NOTE: The National Contact Point of NMGs is the person who provides administrative and technical support to the NMGs coordinator.

5. If there is a different or additional figure in your structure, please describe its role and profile*:



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National Genomics Plan

6. Do you have a national genomics plan? *

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

7. Webpage (link) of the document:

8. Contact person in your country for the implementation:

Name	Affiliation	e-mail address
<input type="text"/>	<input type="text"/>	<input type="text"/>

9. Please provide a short explanation of scope and size of the programme:

10. If there is a national genomics plan, is it aligned with the 1+MG initiative?

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

National 1+MG Roadmap

11. Do you have a national roadmap related to the 1+MG initiative in your country?*

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

12. How will the 1+MG initiative's roadmap be implemented in your country? Is it through the national genomics plan (if it exists)? Please provide a brief explanation and/or additional public information (e.g. report, website), if available.

National Mirror Groups Composition and Functioning

13. At what stage is your country in establishing a 1+MG National Mirror Groups? Please select one of the following options:*

<input type="checkbox"/>	No tangible activities yet (No expert nominations for the NMGs yet)
<input type="checkbox"/>	Planning/preparing (Not all NMGs exist but expert nominations begin)
<input type="checkbox"/>	Constructing/starting up (Most experts nominated and governance structure beginning to be implemented)
<input type="checkbox"/>	Operational (NMGs filled with nominated experts and an operational governance structure established)

14. Please provide a short explanation to your answer:*

15. Composition of NMGs:

1.- Download [this spreadsheet](#)

2.- Fill in the spreadsheet with the information for your NMG

3.- Send the spreadsheet to B1MG-Coordination@elixir-europe.org with the subject: "B1MG: NMG Composition < country >".

4.- Continue with the survey by checking the corresponding answer below.

<input type="checkbox"/>	Document has been sent
<input type="checkbox"/>	Other (please specify)

16. In the first round of the survey, three typical organisational models of NMGs were identified. Please indicate whether your organisational model is similar to one of the following three models (see [B1MG D6.6.](#)):*

<input type="checkbox"/>	'Small countries with National Genomics Strategy' model: A single 'core group' with people involved of ministry, experts, industry and all the stakeholder representation coordinating 1+MG and National Genomics Strategy implementation in a country.
<input type="checkbox"/>	'Big countries with National Health Service System' model: One NMG for each WG of the initiative. These 11 NMGs are coordinated by the national representative of each WG in the initiative and each group is composed of between 5-7 experts (approx.).
<input type="checkbox"/>	'Countries starting to set up their NMGs' model: One NMG composed of national representatives for the 11 WGs of the initiative.
<input type="checkbox"/>	Other organizational model

17. If you have other organizational model in the country, please provide a short explanation about your model:

18. Expert nomination process to join the NMGs:*

19. Governance structure in the NMGs:*

20. Does the NMGs have a specific 'Terms of reference' from the government?*

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

21. In which way?

22. Communication process with and among NMGs (please describe how often NMGs exchange information and/or meet):*

23. Do you organize activities at national level with the NMG?*

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

24. How often?

25. What kind of activities?

26. Is there financial support for the operation of the NMGs?*

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

27. In which way?

NMG links to the 1+MG Initiative

28. How active are NMGs members in the initiative? (value the activity of NMGs between 1 and 5, being 1 not active and 5 very active)*

1	2	3	4	5

29. Do you think there are sufficient links between NMGs and the European Initiative?*

	Yes
	No

30. If not, please describe how they could be further involved/engaged.

