



Beyond One Million Genomes

D6.7

Guiding principles and best practices examples for mirror groups

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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 NMGs by taking into account the peculiarities of the different National Health Systems and governance. 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 roughly half 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 adoption of "Terms of references" by several countries.

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

¹[1+Million Genomes Roadmap 2020-2022 – adopted on 4 February 2020 by the signatories of the Declaration.](#)



These data have 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.

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.

According to the results obtained, we prepared a second survey where we added several new questions to improve it and have a more complete vision of the situation of NMGs (see section 9.1). The survey was circulated in February 2022.

4. Description of work

4.1 Second National Mirror Groups Survey

To know the degree of engagement and development of the countries in relation to the initiative and the evolution of the NMGs , a second survey (see section 9.1.) was prepared in which some questions have been added and other have been slightly modified to avoid confusions, as follows:

4.1.1 Profile and contacts

Goal: To identify the main point of contact in order to monitor NMG progress over time.

- Representative of WG1.



- NMGs Coordinator.
- National Contact Point of NMGs.
- Different or additional figure for NMGs.

4.1.2 National Health Genomics Plan

Goal: collect information relevant to evaluate long term sustainability

- 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

Goal: Capture national implementation of the NMGs

- 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

Goal: Capture maturity (self-assessment) of the NMGs as well as the structure

- 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

Goal: Capture level of interaction between the NMGs and the 1+MG Initiative WGs

- 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, more detail about the responses received:

Table 1. Replies received from countries

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	IE	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
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

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

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



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

Table 2 Profiles and contacts

Profile and contacts	Yes	No	Same WG1 representative
NMGs Coordinator	4/19	1/19	14/19
NCP of NMGs	10/19	1/19	8/19
Different or additional figure	4/19	15/19	-

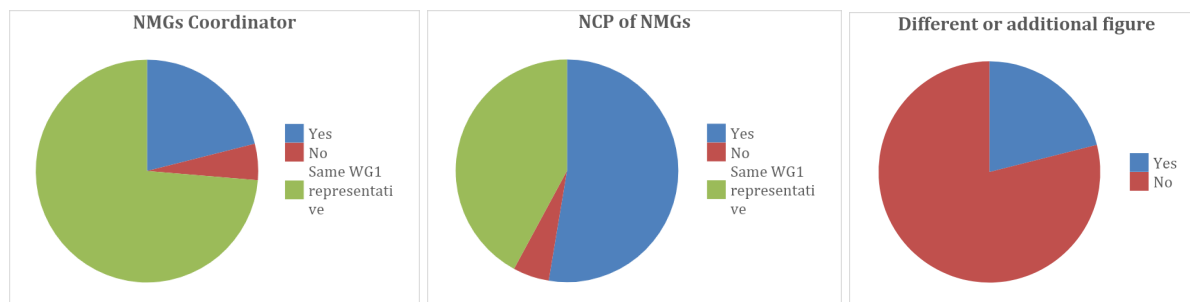


Figure 1 Profiles and contacts, graphical representation

Table 3 National Health Genomics Plan (NHGP) and 1+MG Roadmap

National Health Genomics Plan (NHGP) and 1+MG Roadmap	Yes	No
Have National Health Genomics Plan	9/19	10/19
Have National 1+MG Roadmap	8/19	11/19
Alignment : NHGP- National 1+MG Roadmap	6/9	3/9

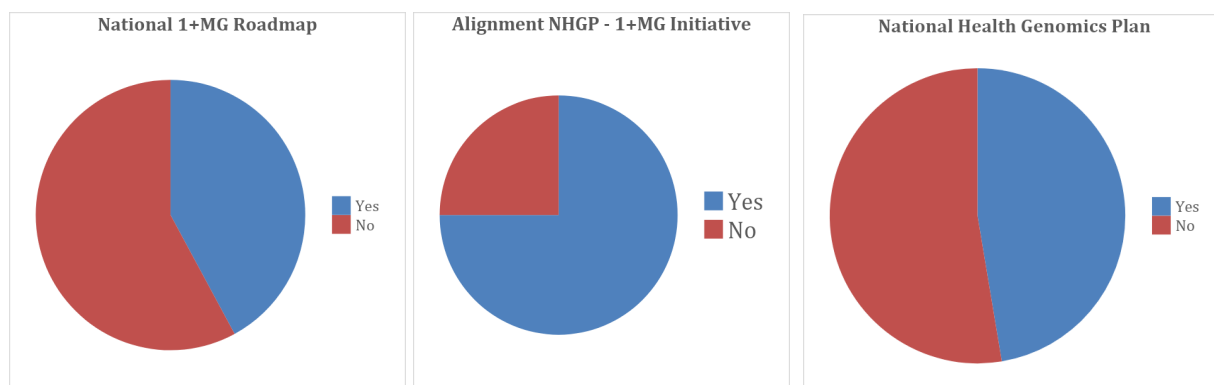


Figure 3 National Health Genomics Plan (NHGP) and 1+MG Roadmap

Table 4 National Mirror Groups composition and functioning

National Mirror Groups composition and functioning	No tangible activities yet	Planning/preparing	Constructing/starting up	Operational
Stage in establishing NMGs	1/19	4/19	5/19	9/19
	Yes		No	
Expert nomination process	12/19		7/19	
Communication process ⁴	12/18		6/18	
Governance structure	12/19		7/19	
Activities organized at national level	12/19		7/19	
Funding or specific assignment	6/19		13/19	
Terms of reference	4/19		15/19	

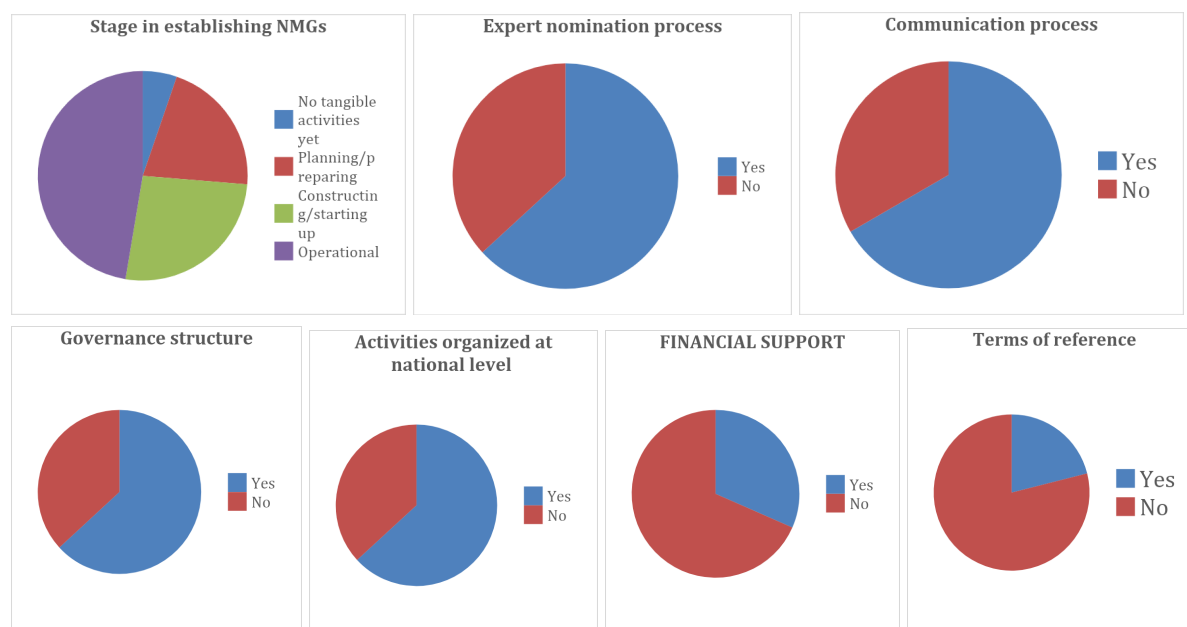


Figure 4 National Mirror Groups composition and functioning

Tables 5 NMGs' organisational model

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	Other organization al model

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

⁵ 'Small 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 of 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.

⁶ 'Countries 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.

			System' model ⁷	
Organisational model of the NMGs	6/19	7/19	2/19	4/19

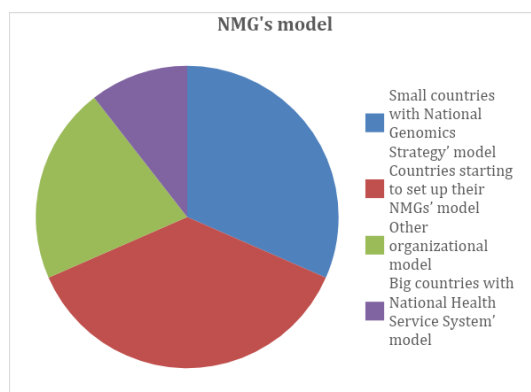


Figure 6 National Mirror Groups model

Table 6 NMG links to the 1+MG initiative

NMGs links to the 1+MG Initiative	Value 1	Value 2	Value 3	Value 4	Value 5
How active are NMGs members in the initiative	2/19	0/19	5/19	7/19	5/19
	Yes			No	
Engagement between NMGs and initiative	15/19			4/19	

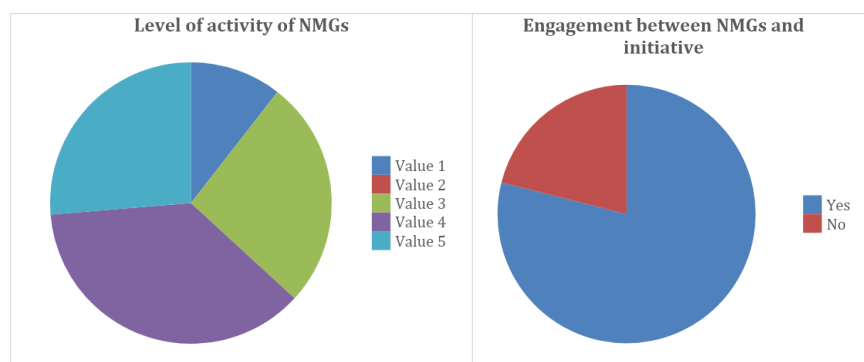


Figure 7 Level of activities and engagement

⁷ 'Big countries with National Health Service System' model: these countries have established a 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.

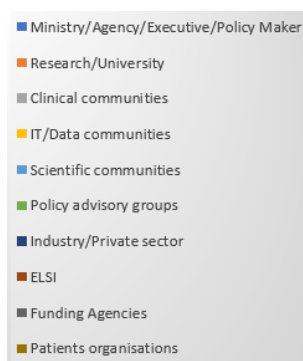
5.2. NMGs' Composition Results

On the current 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) out 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), since for each WG there is a NMG with several experts in it.

5.2.2. Type of Stakeholders



Regarding stakeholder representation, **the composition of NMGs are quite heterogeneous among countries**. The most represented group in NMGs in most countries are experts from **'Research/University'**.

⁸ The 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.

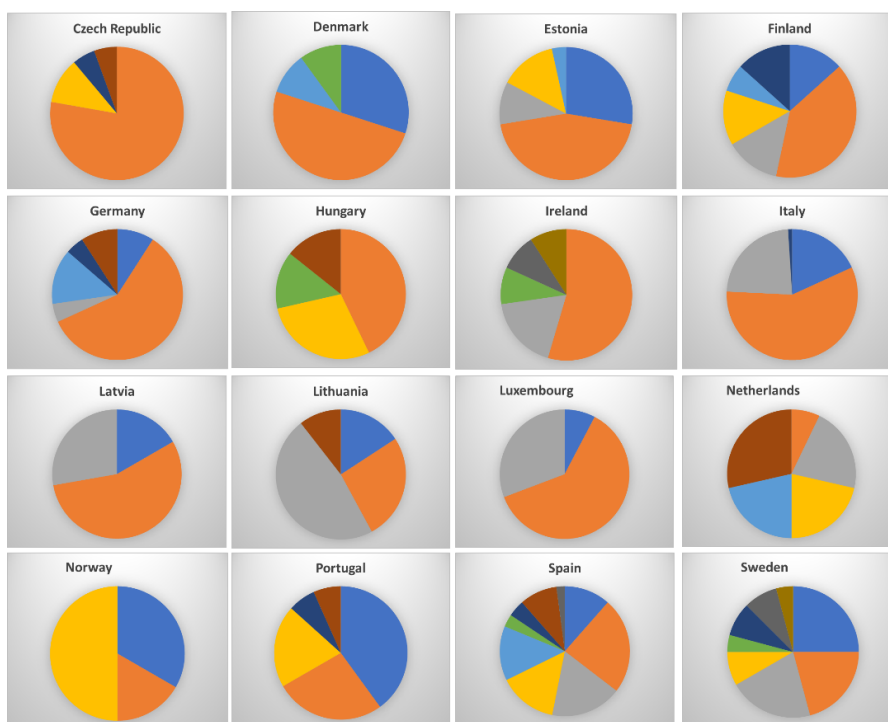


Figure 8 National Mirror Groups stakeholders composition

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 among a variety of stakeholders.
- Only two countries (**SE**, **IR**) have representatives of '**Patient Organizations**' in their NMGs.
- '**Funding Agencies**' are represented only in 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 their 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 shown 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 concert with the NMG.

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

Within the time between the two surveys, a number of National Genomics Plans aligned with the 1+MG Roadmap have been developed. 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 shown that almost half of the NMGs (47,37%) are "Operational". However, some countries that chose this option have not established neither their governance nor an 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 one which best 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 as "Big countries with National Health Service System". On the other side, PT, EE and NL have "Other organisational models".

- **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.

To better understand the differences between the different NMGs, we analysed the data obtained in the survey from two perspectives:

1) According to the organisational model of the NMGs



Table 7 Countries per organisational model (self declared)

Small countries with National Genomics Strategy' model	Countries starting to set up their NMGs' model	Big countries with National Health Service System' model	Other organisational model
Czech Republic Germany Hungary Ireland Latvia Luxembourg Malta	Belgium Denmark Finland Lithuania Norway Sweden	Italy Spain *Note that this countries are at operational level.	Estonia Netherlands Poland Portugal

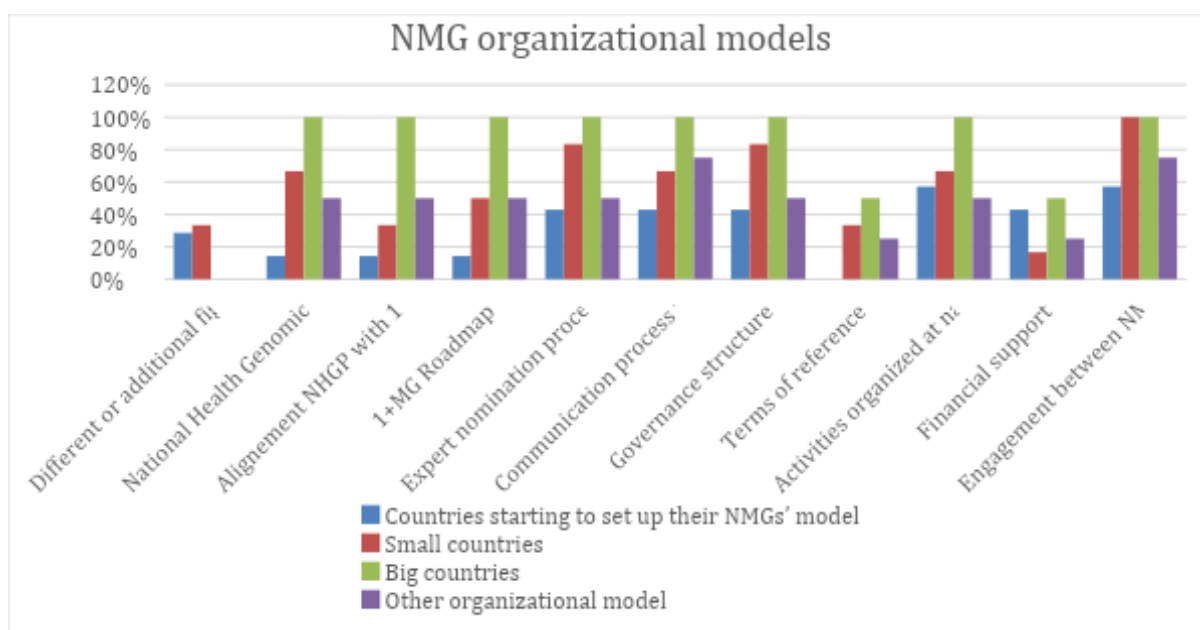


Figure 9 Countries per organisational model (self declared)

2) According to their operational status

Table 8 Countries per operational status (self declared)

Planning/ preparing	Constructing/ starting up	Operational
Czech Republic Ireland Malta Netherlands	Germany Hungary Latvia Norway Estonia	Luxembourg Belgium Denmark Finland Lithuania Sweden Italy Spain Portugal

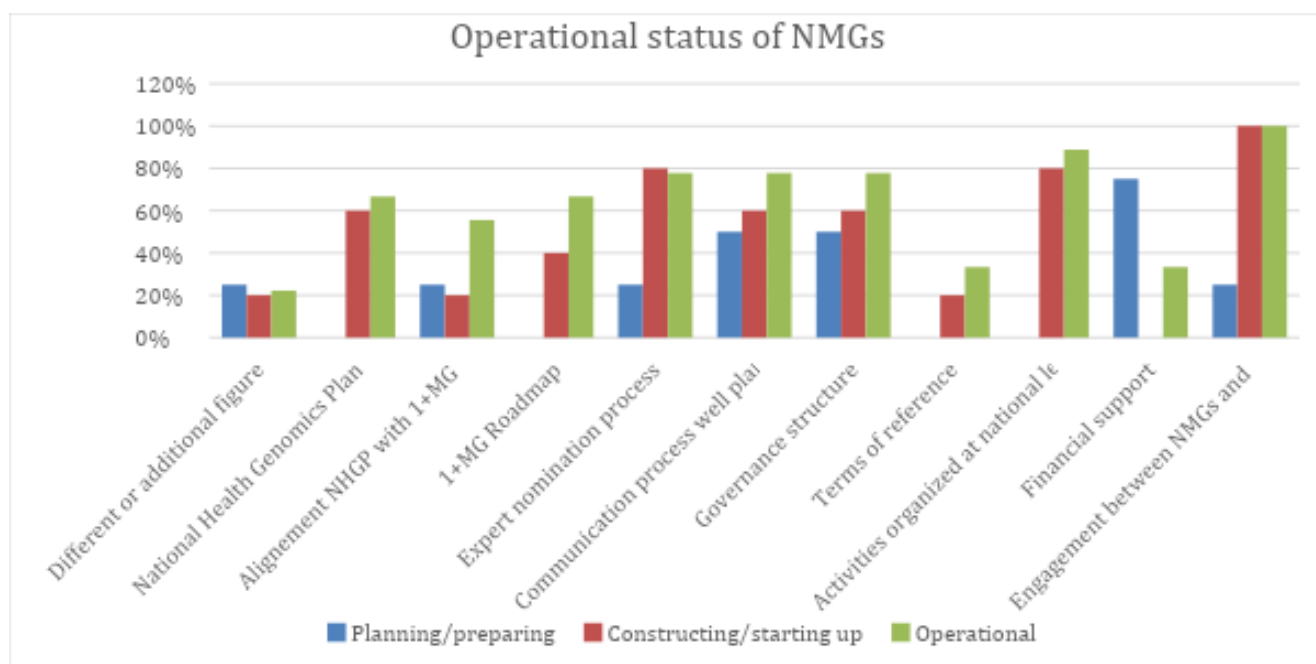


Figure 10 Countries per operational status (self declared)

When looking at these bar charts, we may conclude the following:

- There is no common pattern for countries starting to set up their NMG's model, small/big countries or other organisational models.
- Operational NMGs have better alignment with the initiative (National Health Genomics Plan, 1+MG Roadmap), more activities organised at national level, well-defined governance structure and communication and expert nomination processes.
- The terms of reference started to be developed during the constructing/starting up phase, not before.

6.3.2. Communication and governance

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

- **FI:** The National Coordinator chairs the meetings, with a formal agenda, minutes and to-do lists. The Secretariat for the Finnish implementation (FI+MG) at the Ministry manages its 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 it is supported by the Secretariat at the Ministry (FI+MG SEC). Finland contributes to the 1+MG through the leadership in Working Groups 5, 7 and 11 as well as by its 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 (coincident 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. Additionally, the Carlos III Health Institute, representative of Spain in this initiative, belongs to the Science Ministry and also has strong links with the Health ministry, and its main role is to promote R&D in the Spanish Health Ecosystem. For that reason, 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 health research institutes, universities, national centres for cancer and sequencing, etc.

Similarly to governance, communication procedures have also improved among countries.

6.3.3. Expert process nomination

In most countries a Ministry is involved in the appointment of NMG members, usually the Ministry of Health. Those countries with a larger number of components in their NMGs that responded 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 appointment. 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 "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.
- **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.

6.3.5. NMGs composition

In general, the composition of 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 level of 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. Four NMGs lack representation from Ministry/Agency/Executive/Policy Makers. 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 the most heterogeneous NMG composition in terms of stakeholders are: ES and SE.
- The countries with more variety of 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”
- Six countries have NMG representation from 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.
- LT and ES have the same type of stakeholders, but the percentage has changed between surveys.
- HU, PT and LV are the countries where NMG composition has changed the most between the 1st and the 2nd survey particularly on the type of stakeholders involved.

6.4. NMGs links to the 1+MG Initiative

Most of the NMGs considered that there is an important level of engagement between their NMGs and the initiative. This number has increased in comparison with the first survey. The level of activity of the NMGs have also increased.

Nonetheless, the activities organised at national level and the funding support have remained stable since the first survey. Regarding financial support, more than a two-thirds of the NMGs have declared that they receive some financial support. However, 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
- Establishment of the governance structure
- Level of activity of the NMGs
- Engagement between NMGs and the initiative
- Some countries have signed “Terms of reference”
- Better definition of the compositions of NMGs
- Some countries have grown their NMGs in terms of members involved.

According to the last survey results, FI, IT, ES and PT are the countries that have established their NMG at operational level, with a well-defined governance, expert nomination process, regular communication activities among the NMGs and inside each NMG-WG, a high level of 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 of the survey to make some free-text suggestions:

- Continuous funding of the activities of 1+MG WG / NMGs could improve involvement of the members. Currently most of the participants contribute on a voluntary basis which does not bring necessary commitment required.
- The expertise required by the participants in the 1+MG WGs/NMGs is in high demand nationally (within the healthcare system and in national projects) and at the European level which creates a workload issue with the participants. As a consequence, the flow of information across genomic initiatives should be better organised e.g. through a central 1+MG dashboard for genomics initiatives as well as WGs / NMGs to avoid them getting lost.
- 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 defined on the way.
- The work of active members of the WGs needs to be acknowledged clearly.
- Although in general there is a good engagement of the 1+MG WGs / NMGs with the initiative, it is true that it depends mostly on the WG topic and the relevance expertise available in the countries.

8. Recommendations

A meeting of 1+MG WG1 - Scope, stakeholders and Governance took place on the 22nd of February 2023. This meeting had a dual objective: 1) to inform the members of the WG1 about the recommendations, and 2) to complement the recommendations having a joint reflection of possible next steps to optimise the functionality of the NMGs.

We include here the ideas that emerged during that meeting with WG1 to get additional feedback in addition to the analysis of the information provided by the NMGs.

After analysing the results from the first and the second surveys together with the WG1 members, some recommendations can be made:

Recommendations for 1+MG Group Members

- A **“Terms of reference”** would help to define the mandate, tasks and activities of NMGs and strengthen the collaboration between the Ministries and the other stakeholders involved. This document would clarify what is expected from the NMG in terms of objectives, tasks, national roadmaps and operational procedures such as the expert nomination process, governance structure, communication procedures, alignments with national initiatives and source of funding. NMGs must be explicitly required to promote the adoption, at the national level, of 1+MG recommendations and guidelines (see 1+MG Framework <https://framework.onemilliongenomes.eu/>) which reflect the agreement of the national experts nominated by the 1+MG Group Members. In doing so, NMGs must liaise with current and forthcoming national genomic initiatives, facilitating the flow of high-quality genomic and phenotypic data that is 1+MG proof to the 1+MG Node to make



it available for research, innovation and policy making in accordance with the 1+MG Data Governance.

- **Establishment of NMGs:** It is still necessary to establish minimum rules for the establishment of NMGs in terms of structure and operation, which are 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. Countries should look at the three models to identify and select which could work better for them and according to it, establish the term of references and the governance of the National Mirror Groups defining a clear process for the selection of their members and the representatives that would join the 1+MG WGs coordinating the activities across Europe.
- **Stage in establishing NMGs:** Although most of the countries self declare to be at the “operational” level, some of them have not yet established their governance, expert nomination process, communication procedures... Therefore, countries should re-assess and improve their NMG Governance, when applicable, and ensure the involvement of the relevant national experts within the NMG and to the corresponding 1+MG WGs
- **NMGs Funding:** Ways should be sought through which the work of the NMGs is continuously funded by countries, either through the financing of personnel in charge of their management, or through incentives that increase the engagement of the experts with the NMGs and the initiative. Additionally, if 1+MG Group Members consider the 1+MG initiative as a key priority for their country, they should promote the allocation of the required funds for the NMGs to be effective.
- **NMG role once the 1+MG legal entity is established:** A joint reflection should be made about the role of the NMGs once the 1+MG set up their governance model and legal entity. A natural evolution would be for the NMGs to become the 1+MG Node responsible for the deployment and operation of the 1+MG activities in the country.

Recommendations for 1+MG WG1 and NMGs

- **Profiles and contacts for the management of NMGs:** Effective communication of the role and responsibilities of the NMGs as well as facilitating access to them has been identified as an action that increases the alignment between the national implementation (NMGs) and the initiative (1+MG WGs). Therefore, it is necessary to define and clarify the profiles and contacts for the management of NMGs and to communicate them at the national and EU level e.g. using tools like the <https://framework.onemilliongenomes.eu/national-implementation>



- **Stakeholders' representation:** Countries should be encouraged to:
 - Enrich their NMGs to have as proper representations of stakeholder that would facilitate the deployment and operation of 1+MG activities at the national level
 - Include 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 healthcare providers as end users.
 - Appoint representation in all of the WGs to ensure permanent feedback and coordination: 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 all 1+MG developments and progress in the different working groups translating into the implementation at national level.

- **Involvement of Policy Bodies.** The involvement of policy bodies is essential for the proper functioning of the NMGs and should be at different levels. Ideally, experts with a technical profile from the Ministries involved in the 1+MG initiative should follow up the activities and work of the NMGs, in order to provide information and feedback from the Ministries. High-level representatives should be involved in the decision-making processes taking place within the 1+MG Group according to the 1+MG governance structure. Moreover, they could also play an active role in the promotion of the 1+MG initiative, to increase awareness, participation and mobilise experts that may importantly contribute to the initiative. Therefore, NMGs should work in collaboration with the Policy Bodies, establishing a bidirectional communication channel.

- **Engagement between NMGs and the initiative:** it is necessary that there is clear coordination between the representative within the 1+MG Group of the initiative and the NMG representative or coordinator. This engagement is fundamental for initiative because of its bottom-up approach. To boost this cooperation, it could be helpful to schedule, at least once a year, face-to-face meetings where NMGs leaders could interact with 1+MG Group members, WG leaders, and other NMG Coordinators. This should improve the perception of the 1+MG as a very active initiative and increase the strategic alignment between the European level and the national implementation. Another measure is to organise some thematic workshops to exchange experiences from each of the NMGs in the different aspects of the 1+MG implementation.

- **Creating a communication strategy:** It is important, for the success of the NMg, to bring together the NMGs , including the representatives on the 1+MG WGs , but also the national stakeholders that need to be involved to facilitate the deployment of the initiative at the national level. Several actions could be considered such as organising a National Symposium, to create a 1+MG National Newsletter and 1+MG Node website



(using 1+MG branding and url, e.g. “country.onemilliongenomes.eu”) in national language or adapting the internal deliverables from a more general view.

- **Additional entities:** although it is not a key issue, could be a good way to align other constituted groups involved in similar projects/programmes/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.
- **Organisational aspects.** All the information generated within the 1+MG framework is being made available via the (<https://framework.onemilliongenomes.eu/>) which include a section to support the national implementation (<https://framework.onemilliongenomes.eu/national-implementation>) which is now available to the NMGs to disseminate their progress and specific recommendations and guidelines (in the national language that complement the EU level recommendations with the national regulations and aspects that need to be consider.
- **NMG Plan:** 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.
- Finally, by taking all these recommendations into account, a brief guide is added as Annex 1 to facilitate the setting up and the functioning of the NMGs. Some key aspects and a description of the role of the NMGs, principal actors and composition were included (see annex 1).



9. Annexes

The Annex 1 presents a General guidance for 1+MG MMg that could be distributed detached from this document as such it reiterates some information detailed above to make it self-contained.

Annex 1: General guidance on 1+MG National Mirror Groups

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1. Definition

The National Mirror Groups (NMG) 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 in terms of approaches with respect to the 1+MG initiative, mirror groups are set up in different configurations.

Mission:

- Facilitate country experts and policy makers to gain access to information from the initiative and ensure the alignment of Member States with the objectives of the initiative.
- Promote adoption and sustainability at the national level, ensure synergistic implementation in their National Health Systems and provide recommendations to local and European funders.

Role:

- To be "contributors" of content feeding national representatives work, as well as to receive information from the coordinators and transmit it to their national initiatives encouraging adoption (acting as "initiative multipliers"). The NMG experts will provide advice and support in implementing the objectives of the initiative.
- It is expected that a representative of each NMG, designated by the Member States, participates in the annual meetings of the initiative and provides feedback on the outcomes of the EU projects that support the initiative.



2. Composition

The 1+MG working groups that might guide the structure of national mirror groups are the following:

1. Scope, stakeholders and Governance
2. Ethical, Legal, and Societal Issues
3. Common standards and minimum datasets for clinical and phenotypic data
4. Good sequencing practice
5. Federated, secure, interoperable and privacy-respecting framework and access governance
6. Health economics and outcome research
7. Involvement of the private sector
8. Use case - Rare diseases
9. Use case - Cancer
10. Use case - Common and complex diseases, Polygenic Risk Scores
11. Use Case - Infectious Diseases
12. Genome of Europe

Typically, a NMG is a group of national experts working on a domain covered by one of the 1+MG Working Groups. However, especially in smaller countries, a NMG may be a group of all national experts contributing to 1+MG in all WGs. Each NMG may have:

- A Scientific Coordinator
- Size: the most common case is that NMGs composition includes between 10-20 experts, depending on the configuration at national level.
- A wide geographical representation in the country
- Adequate gender balance
- Representatives of all types of stakeholders: Ministry/Agency/Executive/Policy Maker, Research/University, Clinical Communities, IT/Data Communities, Scientific Communities, Policy advisory groups, Industry/Private Sector, ELSI, Funding Agencies, Patients organisations.

3. Roles and profiles for the management of NMGs

In each NMG we can distinguish the following profiles:



NMG Coordinator / WG1 representative

Liaison with WG 1 of the 1+MG initiative. In most of the countries the WG1 representative is the main coordinator of the NMG(s) and of all national efforts and actions related to 1+MG.

It is necessary that there is clear coordination between the nominated national representative in the 1+MG Group of the initiative and the NMG coordinator. This engagement is fundamental in this initiative because of its bottom-up approach.

National Contact Point

This is the person assigned to assist the NMG Coordinator as the first contact point for the national experts and other stakeholders on all matters pertaining to 1+MG. Several countries assigned this role to the WG1 representative.

Scientific Coordinators

Experts leading and coordinating the work of each of the NMGs.

Additional functions

1+MG NMGst could be a good way to align other constituted groups involved in similar projects/programmes/activities at national level. They could act as an external board if they were not interested in participating as individual members in a specific group within the NMG.

Example: Finland has an Expert Group on Genomic Medicine, hosted by THL, which advises the Finish 1+MG NMG on the clinical use of genomics in the country.

Members

They are expected to be experts in their respective NMG/WG topics and to participate, contribute and drive the work of the group. Examples of member participation includes:

- Develop and draft working-group documents;
- Contribute ideas and knowledge to working group discussions;
- Act as liaisons between the Working Group and their respective stakeholder groups or constituencies;

4. National Genomics Plan and National 1+MG Roadmap

National Genomics Plan

NMGs link up to national and regional activities thereby providing a coordination mechanism to the goals of the 1+MG declaration and enabling alignment of national genomics programmes in each respective country.

National 1+MG Roadmap



The 1+MG Roadmap needs to move into implementation by involving the signatory countries at several levels: the country representatives in the initiative, experts involved in 1+MG Working Groups, and national coordination via NMGs. The objective should be to have NMGs established in all signatory countries.

With the National Mirror Groups, a strong effort will be made to disseminate the roadmap in each participating country to key decision makers in governments.

5. NMG status and models

Status level

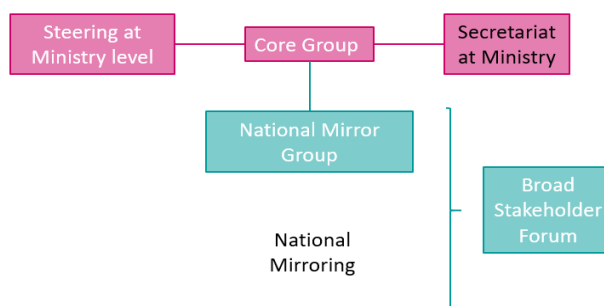
The status of the NMGs could be classified as follows:

- 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)

NMG models

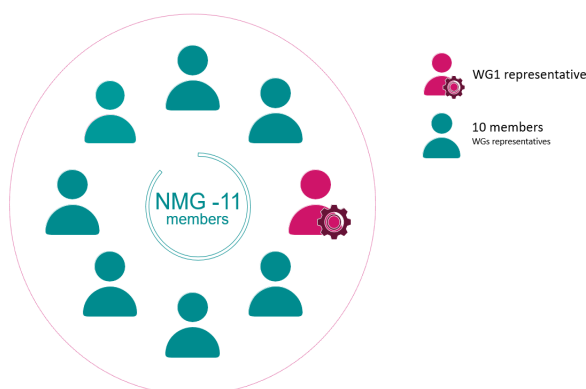
On the path to establish fully functional NMGs countries have transitioned different stages or adopted different organisation that fit to the needs, resources and current involvement of the country in the 1+MG initiative

Countries with NMGs to be established at the early stage, and in countries with limited resources to connect to the initiative, tend to establish a '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.

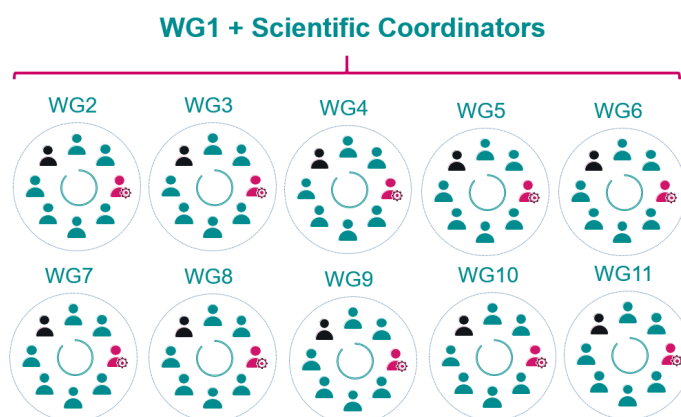


- **Countries starting to set up their NMGs:** in these countries they have formally established a NMG composed of national representatives (individuals) for the 12 WGs of the initiative. In this case there are no national WGs bridging wider representation of experts in the area. This is normally an intermediate stage to the development of a fully functional NMG.





- Countries with fully developed NMG model:** these countries have established a NMG with dedicated WG for each WG defined by the 1+MG initiative.. These NMGs WGs are coordinated by the national representative of each WG in the initiative and each group is composed of between 5-7 experts. The NMG is fully aligned with the 1+MG initiative establishing the baseline for an effective deployment of the initiative actions at the national level.



6. Operational aspects

Expert nomination process

The expert nomination procedure within the NMGs could play a key role in the manner NMGs commit. Each country should develop mechanisms to add experts not only based on knowledge and the experience criteria, but also with motivation and availability to dedicate their time to push forward the 1+MG initiative.

In the majority of expert nomination processes of the NMGs, the Ministry of Health is directly involved in the appointment of their members. However, countries present a “big size” model follow a different expert nomination process: the coordinator of each NMG-WG nominates or approves the appointment of new members.

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.

Governance structure

The synthesis and the structure of the National Mirror Groups will contribute to the implementation of the objectives of the Working Groups.

The interim governance structure should ensure commitment/engagement and alignment to national and regional governance, expertise, knowledge and activities.

Some examples of a well-defined governance are the following countries:

- FI: The National Coordinator chairs the meetings, with a formal agenda, minutes and to-do lists. The Secretariat for the Finnish implementation (FI+MG) at the Ministry manages its 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 it is supported by the Secretariat at the Ministry (FI+MG SEC). Finland contributes to the 1+MG through the leadership in Working Groups 5, 7 and 11 as well as by its 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 provides 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 (coincident 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. Additionally, the Carlos III Health Institute, representative of Spain in this initiative, belongs to the Science Ministry and also has strong links with the Health ministry, and its main role is to promote R&D in the Spanish Health Ecosystem. For that reason, 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.

Communication process

NMGs should be an active network, capable of providing the feedback from the countries to the 1+MG on how to achieve the implementation of the initiative at the national level and this may comprise a continuous commitment from both sides (1+MG WG and NMGs). Meetings



independent from the WG-Special Group meetings should be taken place in order to boost the activity of the NMG-WG.

The arrangement of meetings on a regular basis may not be a successful strategy for the permanent and correct engagement of the NMG members. Regular fixed-meetings such as teleconferences, could be perceived as an obligation and this could diminish participant engagement.

All the information generated within the 1+MG framework could be overwhelming for NMGs. In order to make the NMGs more operational, the relevant documents could be centralised in a repository (following the Spanish model) or it could be helpful to create a section on the 1+MG website with this aim. In addition, other actions could be to elaborate a google calendar, a dashboard and a roadmap with key points for actions.

Terms of reference

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.

It would be very useful to set up a “Terms of reference” document to secure the mandate of the NMGs. This document would clarify what is expected from the NMG in terms of objectives, tasks, national roadmaps and operational procedures such as the expert nomination process, governance structure, communication procedures, alignments with national initiatives and source of funding (if possible).

Examples of terms of reference:

- 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 with the task of following up 1+MG.

In addition, on the basis of Finland experience, an additional NMG Plan 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.



7. 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.

8. Stakeholder involvement

NMGs, in collaboration with Stakeholders, will create a space for dialogue to build an agenda that will include the following issues:

- a decision-making framework for public-private participation and increased health literacy among stakeholders;
- a framework for the future to facilitate the integration of emerging health technologies into health systems and
- identify future cooperation mechanisms between stakeholders inside and outside the EU

Stakeholder representation

There are some actors (stakeholders) that should be encouraged to participate in the NMGs:

- 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.

The involvement of policy bodies is essential for the proper functioning of the NMGs and should be at different levels. Ideally, experts with a technical profile from the Ministries involved in the 1+MG initiative should follow-up the activities and work of the NMGs, in order to provide information and feedback from the Ministries. High-level representatives should be involved in the decision-making processes taking place within the Commission Special Group (1+MG Group) according to the 1+MG governance structure. Moreover, they could also play an active role in the promotion of the 1+MG initiative, to increase awareness, participation and mobilise experts that may importantly contribute to the initiative. Additionally, if Policy Bodies consider the 1+MG initiative as a key priority for their country, they may allocate certain funds for the NMGs.



For genomic data use to be successfully adopted by healthcare, it is fundamental that a close collaboration is established with healthcare systems stakeholders in each country, to deeply understand the challenges and expectations of effective data sharing and data usage, so that the generated framework becomes effectively useful and sustainable.

As final recommendations, countries should be encouraged to:

- Enrich their NMGs to have as much stakeholder representation as possible.
- 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 end users who are 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 involve stakeholders in all the NMGs for the 1+MG WGs to have the opinion and perspective from the national level experts and 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.


Activities at national level

Efforts should be made to create a communication value and wider the 1+MG audience.

It is important to bring together not only members and NMGs, but also other stakeholders. Several actions could be considered such as organising a National Symposium, to create a 1+MG Newsletter and website or adapting the internal deliverables from a more general view.



Annex 2. 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*:



Beyond One Million Genomes
B1MG has received funding from the European Union's Horizon 2020 Research and Innovation programme under grant agreement No 951724





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?*

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

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

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