



Beyond One Million Genomes

## D6.6 - Analysis and assessment of mirror groups

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Beyond One Million Genomes

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**B1MG**

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# 1. Executive Summary

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. Furthermore, some of these member states are still in the process of establishing them.

For this reason, it is necessary to map the configurations of the NMGs in the different countries to identify the commonalities on the NMG configurations and if these configurations can be correlated with peculiarities of the different National Health Systems across Europe and with the implementation of the initiative at the national level. This mapping will also help us to know how and to what extent NMGs connect with their national initiatives.

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

- The development of an initial factsheet<sup>1</sup> ([see section 10.1](#)) 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.
- A survey<sup>2</sup> ([see section 10.2](#)) has been circulated among the participating Member States and the Observer Countries of the initiative and was analysed the different existing mirror groups assessing its structure, composition, governance, and operating modes and if they were correlated with their national structures.
- 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.

After analyzing the results, it has been found that in most of the countries (10 of 19) the WG1 representative is the main figure that coordinates the NMGs that only 22.22% of the countries (4 of 18) consider that their NMGs are 'Operational', and just over half of the countries consider that there is engagement between their NMGs and the initiative. 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 representation of the research and university communities and not so much of the clinics.

To achieve the goals regarding NMGs set up in the roadmap of the initiative<sup>3</sup>, it would be recommendable that at least 75% of the countries have their NMGs operational by the end of 2021, that all NMGs have a high engagement with the initiative and they be aligned with national initiatives and countries feed their NMG with stakeholders related with patient organisations, industry and clinical communities.

<sup>1</sup><https://drive.google.com/file/d/1M2tgA3VmPN19InabhR77W9t3e5qSh81Z/view>

<sup>2</sup><https://www.surveymonkey.com/r/C292V7Q>

<sup>3</sup> [1+Million Genomes Roadmap 2020-2022 – adopted on 4 February 2020 by the signatories of the Declaration.](#)



This data has enabled us to set up some guiding principles and identify a first 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:

Objective/Key Result No & Description	Contributed
<b>Objective 1:</b> 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.	Yes
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.	N/A
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
<b>Objective 2:</b> Translate requirements for data quality, standards, technical infrastructure, and ELSI into technical specifications and implementation guidelines that captures European best practice	
<b>Legal &amp; Ethical Key Results</b>	
1: Establish relevant best practice in ethics of cross-border access to genome and phenotypic data (WP2) by M36	N/A
2: Analysis of legal framework and development of common minimum standard (WP2) by M36.	N/A
3: Cross-border Data Access and Use Governance Toolkit Framework (WP2) by M36.	N/A
<b>Technical Key Results</b>	
4: Quality metrics for sequencing (WP3) by M12.	N/A



5: Best practices for Next Generation Sequencing (WP3) by M24.	N/A
6: Phenotypic and clinical metadata framework (WP3) by M12, M24 & M36.	N/A
7: Best practices in sharing and linking phenotypic and genetic data (WP3) by M12 & M24.	N/A
8: Data analysis challenge (WP3) by M36.	N/A
<b>Infrastructure Key Results</b>	
9: Secure cross-border data access roadmap (WP4) by M12 & M36.	N/A
10: Secure cross-border data access demonstrator (WP4) by M24.	N/A
<b>Objective 3:</b> 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.	N/A
2: Roadmap and guidance tools for countries for effective implementation of Personalised Medicine (WP5) by M36.	N/A
3: Economic evaluation models for Personalised Medicine and case studies (WP5) by M30.	N/A
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 preparation of this deliverable (Analysis and assessment of mirror groups) 3 types of activities have been carried out:

- Preparation of a survey on NMGs, based on the survey circulated by the EC at the beginning of 2020, with a limited number of questions (to be able to answer it in 15 minutes) and with a mix of open and closed questions ([see section 4.2.](#)).
- Bilateral meetings with the representatives of the countries, as an exercise of mutual learning, to give more information about the initiative and the project and to learn about the initiatives, national structures and configuration of the NMGs in the respective countries ([see section 4.3.](#)).
- Preparation of a Factsheet with basic information on NMGs ([see section 4.1.](#)), which will evolve as the initiative progresses.



Through the survey and bilateral meetings we provide an overview of:

- The establishment / lack of establishment, structure, composition, governance and operating modes of National Mirror Groups in the participating Member States and the Observer Countries.
- National Health Genomics Plans in the participating Member States and the Observer Countries.
- Level of implementation of the initiative in the participating Member States and the Observer Countries.

To help Member States understand the mission, role, tasks and structure of NMGs, the factsheet was circulated at the time of distribution of the survey..

This work has been complemented by the work of Work Package 1 related to the Stakeholders Forum and with Work Package 5 through the Country Visits.

## 4. Description of work accomplished

### 4.1 Factsheet ‘National Mirror Groups at Glance’

With the help of the ELIXIR Hub communication department, and with feedback from the rest of the B1MG WP leaders and 1+MG WG leaders, between September and October 2020, a Factsheet was prepared with basic information on the 'ideal' mission, role, tasks and structure of the NMGs based on the information and knowledge that was available in that date.

This factsheet was circulated alongside the first round of mailing of the NMGs survey to help countries clarify and understand this issue.

This factsheet called 'National Mirror Groups at Glance<sup>4</sup>' ([see section 10.1.](#)) is a first version and will evolve at the same pace as the initiative itself and the development of the NMGs.

### 4.2 National Mirror Groups Survey

To know the degree of engagement and development of the countries in relation to the initiative and the NMGs themselves, a survey<sup>5</sup> ([see section 10.2.](#)) was prepared in which the countries were asked about the following topics:

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<sup>4</sup><https://drive.google.com/file/d/1M2tgA3VmPN19lnabhR77W9t3e5qSh81Z/view>

<sup>5</sup><https://www.surveymonkey.com/r/C292V7Q>



#### 4.2.1 Profile and contacts

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

#### 4.2.2 National Health Genomics Plan

- 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.

#### 4.2.3 National 1+MG Roadmap

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

#### 4.2.4 National Mirror Groups composition and functioning

- Stage in establishing a 1+MG National Mirror Group in the country.
- Composition of NMGs.
- Expert nomination process to join the NMGs.
- Communication process with and among NMGs.
- Governance structure in the NMGs.
- Activities organized at national level with the NMGs.
- Funding or specific assignment from the government to the NMGs.
- Degree of formalisation of NMGs in the country.

#### 4.2.5 NMGs links to the 1MG Initiative

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

#### 4.2.6 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 ([see section 10.3](#)):

- 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.
  - Patients organisations.
- Institution.
- Name.
- Charge.
- Gender.
- Region of the country (if applicable or relevant).
- Contact.

### 4.2.7 Survey Circulation

For the preparation of this survey, the questions related to the NMGs that the European Commission had circulated at the end of 2019 and the beginning of 2020 were taken into account and represented a starting point for the preparation of this survey. This helped us to have a first reflection of what the countries had developed in terms of NMGs from the signing of the Declaration in 2018 to the approval of the 1 + MG Roadmap 2020-2022.

This survey was circulated to countries for the first time in **October 2020** with little response success.

After this, a second round of more personalized contacts was made in **November 2020** to try to obtain the necessary feedback.

Starting in January 2021 and throughout the first quarter of 2021, the representatives of the countries in charge of the NMGs were contacted again to finish gathering the missing information and to offer them to have bilateral meetings with them to try to resolve their doubts regarding survey questions and to better understand how NMGs functioned in their countries.

## 4.3 Bilateral Meetings with Countries Representatives

As an exercise of mutual learning, virtual bilateral meetings were held with some of the representatives of the NMGs in the countries<sup>6</sup>.

These meetings took place at the request of the representatives of the countries to clarify their doubts about the survey or by the members of the WP6 itself to clarify some doubts about the responses/or lack of response to the survey.

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<sup>6</sup> Bilateral meetings were conducted with representatives of BE, DK, FI, DE, IT, NO and SI.



The typical guide notes for the bilateral meetings was:

- Presentation of the B1MG project and WP6.
- Presentation of the role of the country representative in the Initiative.
- National initiatives / structure.
- Link with 1+MG.
- Q&A.

## 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.

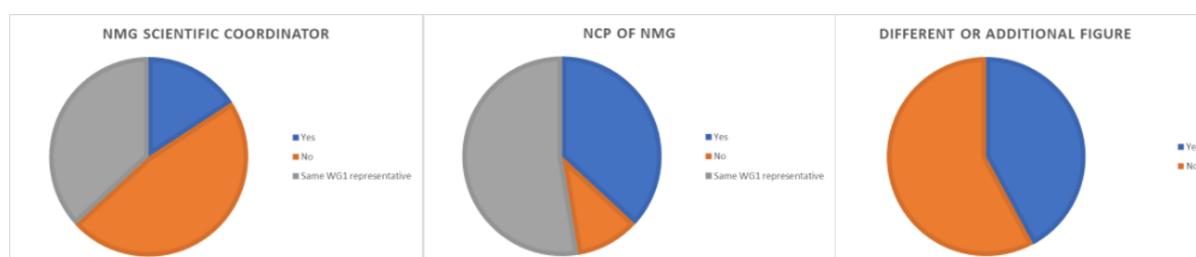
**NOTE:** These results show a picture of the state of the NMGs at the time the responses were submitted. It is possible that during data collection the configuration of the NMGs in the different countries has changed or evolved.

### 5.1. Survey Results

Of the 24 signatory countries, 19<sup>7</sup> countries have responded to the survey, of which 12<sup>8</sup> countries have sent the composition of their NMGs.

The results of the survey are collected in the following table:

Profile and contacts			
	Yes	No	Same WG1 representative
NMGs Scientific Coordinator	3/19	9/19	7/19
NCP of NMGs	7/19	2/19	10/19
Different or additional figure	8/19	11/19	-



National Health Genomics Plan		
	Yes	No
Have National Health Genomics Plan	5/19	14/19

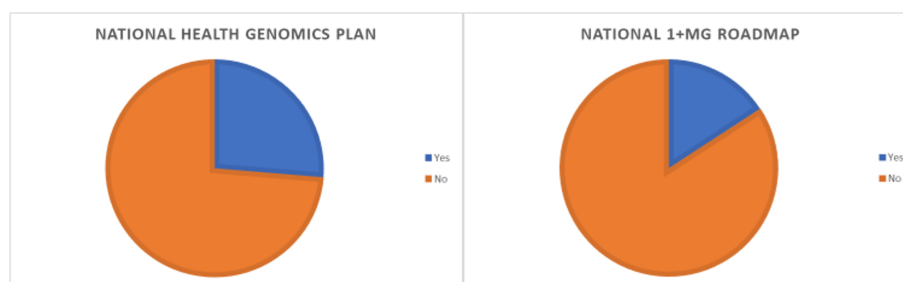
<sup>7</sup> The countries that responded to the survey were: BE, BG, HR, CY, CZ, DK, FI, DE, HU, IT, LV, LT, LU, MT, NL, NO, PT, ES and UK.

<sup>8</sup> The countries that submitted the composition of their NMGs were: BG, CY, CZ, DK, FI, DE, HU, IT, LV, LT, PT and ES.



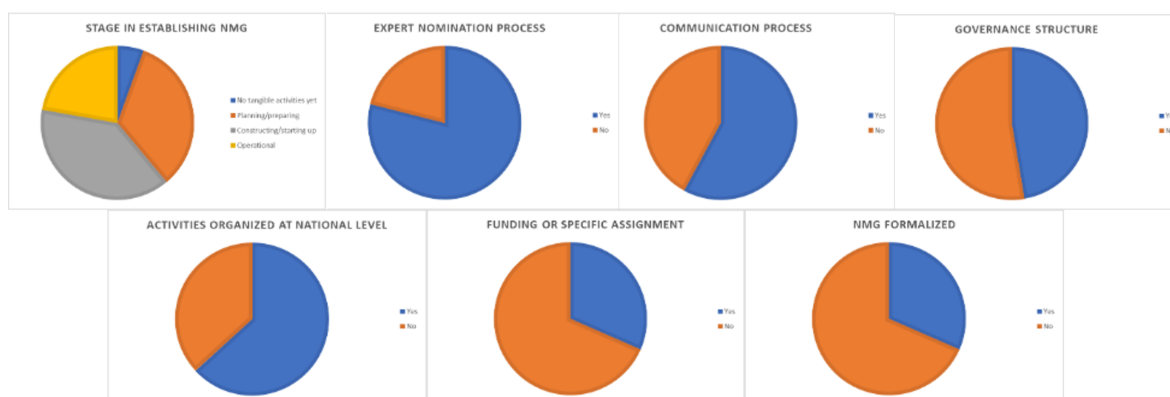
### National 1+MG Roadmap

	Yes	No
Have National 1+MG Roadmap	3/19	16/19



### National Mirror Groups composition and functioning

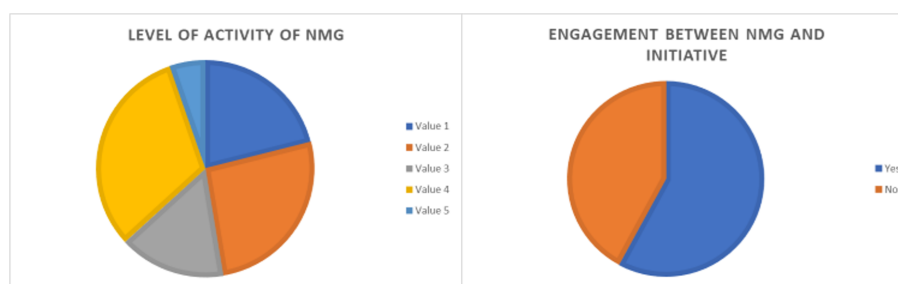
	No tangible activities yet	Planning/ preparing	Constructing/ starting up	Operational
Stage in establishing NMGs <sup>9</sup>	1/18	6/18	7/18	4/18
	Yes		No	
Expert nomination process	15/19		4/19	
Communication process	11/19		8/19	
Governance structure	9/19		10/19	
Activities organized at national level	12/19		7/19	
Funding or specific assignment	6/19		13/19	
NMGs Formalized	6/19		13/19	



### NMGs links to the 1MG Initiative

	Value 1	Value 2	Value 3	Value 4	Value 5
How active are NMGs members in the initiative	4/19	5/19	3/19	6/19	1/19
	Yes			No	
Engagement between NMGs and initiative	11/19			8/19	

<sup>9</sup> This answer is over 18 answers because the UK did not answer this question.



## 5.2. Composition Results

On the current date, 12<sup>10</sup> countries have submitted their composition of experts on the NMGs. Below we analyze the most relevant results.

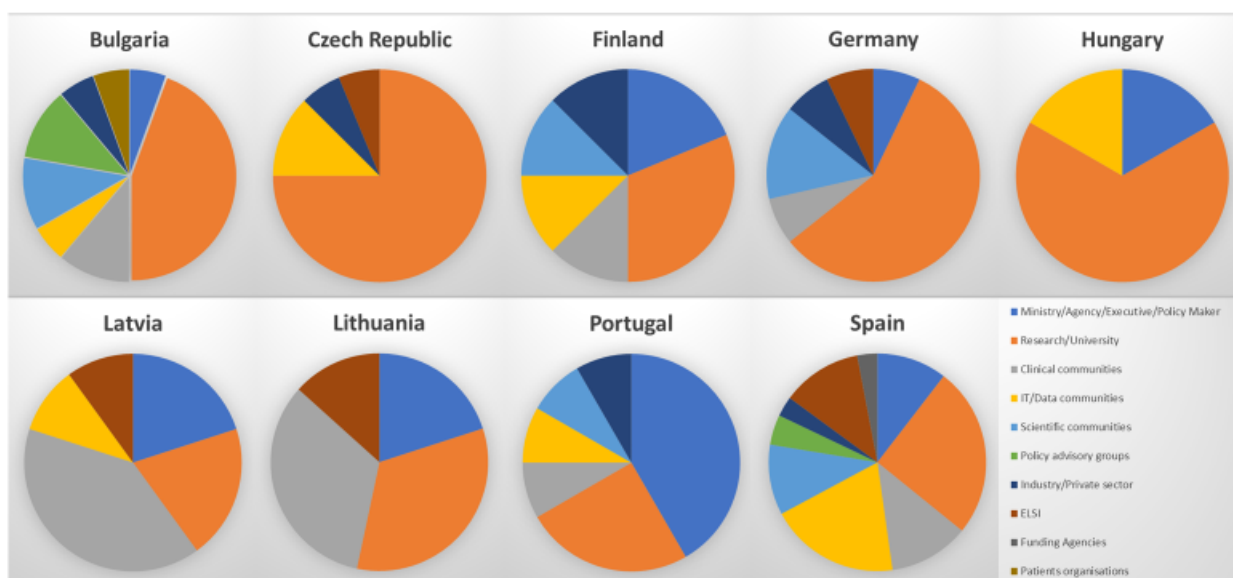
### 5.2.1. Representation in the initiative's Working Groups (WGs) and Size of NMGs

Only 4 (FI, DE, IT, ES) of the 12<sup>11</sup> countries have experts in all the initiative's 11 WGs.

The **most common case** is that **NMGs composition includes between 10-20 experts**<sup>12</sup>. There are two countries whose NMGs are more numerous with an average between 65-75 experts (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 most represented group in NMGs in most countries**<sup>13</sup> **are experts from 'Research/University'**.



<sup>10</sup> The countries that submitted the composition of their NMGs were: BG, CY, CZ, DK, FI, DE, HU, IT, LV, LT, PT and ES.

<sup>11</sup> Hungary has not sent information on which WG its experts belong to.

<sup>12</sup> Cyprus has only one nominated expert among its NMGs.

<sup>13</sup> Italy and Denmark have not sent information about what type of stakeholder their experts belong to.

Three countries differ on this:

- **LV**, where the most represented group is 'Clinical Communities' (40%).
- **LT**, where the most represented groups are 'Clinical Communities' (33.33%) and 'Research/University' (33.33%).
- **PT**, where the most represented group is 'Ministry/Agency/Executive/Policy Maker' (41.67%).

Only one country (BG) has representatives of '**Patient Organizations**' in its NMGs and only another country (ES) has representatives of the '**Funding Agencies**' in its NMGs.

There is representation of the '**Industry/Private Sector**' in the NMGs in half of the countries (BG, CZ, FI, DE, PT, ES).

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

### 5.2.3. Link with National Initiatives

Here are some examples of how countries have linked their NMGs with their national initiatives.

#### Denmark

In Denmark, from now, the idea is to have a NMG composed by representatives of the first 7 WGs and another 4 NMGs of specialists for each of the WGs of the use cases. These groups of specialists will be composed of about 10-15 experts among the 4 NMGs. They will use the recently created National Genome Center, for which they already have specialist experts for the 4 use cases of the initiative to also nominate them as experts of the NMGs.

#### Finland

Finland has connected its NMGs with the national initiative. The structure they have is the following:

Interim NMG will plan and implement actions with two main aims:

- Contribute effectively to the work at EU level in the 1+MG Working Groups.
- Implement the results in Finland.

All 1+MG Working Groups have a representative (and an alternate), their role is clearly understood, and they have regular meetings of this interim NMG.

It should be noted that Finland has a fully functioning group call the National Coordination Group (FI+MG CG), supported by the Secretariat at the Ministry (FI+MG SEC). The Coordination Group mirrors all the Working Groups in Finland and coordinates their work. The Group functions as an interim Mirror Group. However, they do not consider the FI+MG CG as the final NMG as the NMG in their view must have a broader scope as regards policy fields, stakeholders and actors.

Thus, they are in the process of nominating a broader NMG that would bring together about 12 influencers. In addition, we are looking into:



- The policy governance at Ministry level, not only Ministry of Social Affairs and Health but broader, and
- The broader Stakeholder Forum that would have a more open membership bringing together all interested stakeholders and actors.

## Lithuania

In Lithuania There is a National Coordination Committee of Human Genome Research established by the Minister of Health, including representatives not limited to two major University Hospitals of Lithuania, Vilnius University and Lithuanian Health Sciences University, National Cancer Institute, Ministries of Health, Economics and Innovation, Lithuanian Bioethics Committee, Patients' Forum.

The main representatives nominated for the 1+M Genomes Initiative are included in the National Coordination Committee.

## 6. Discussion

It is observed that in most of the countries the WG1 representative is the main figure that coordinates the NMGs. Not many countries have an NCP, a Scientific Coordinator or another specific figure in charge of managing the NMGs.

At the time of data collection, most of the countries are 'Planning/Preparing' or 'Constructing/Starting up' their NMGs. Only 22.22% consider that their NMGs are 'Operational'.

Regarding the functioning of the NMGs, approximately half of the countries have NMGs that operate solidly and only 31.6% (6 countries) have a national budget allocation for their NMGs.

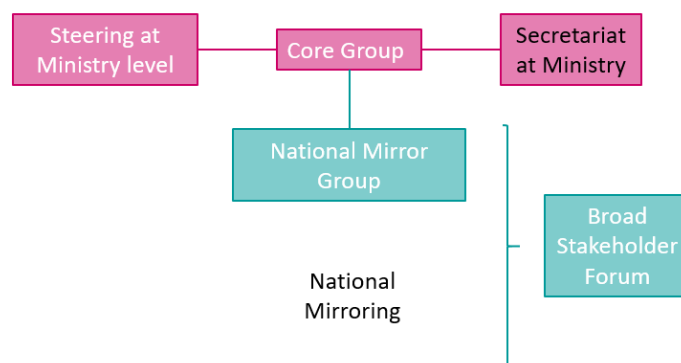
Just over half of the countries consider that there is engagement between their NMGs and the initiative.

In general, the composition of the NMGs is quite heterogeneous among all the countries that have responded to the survey.

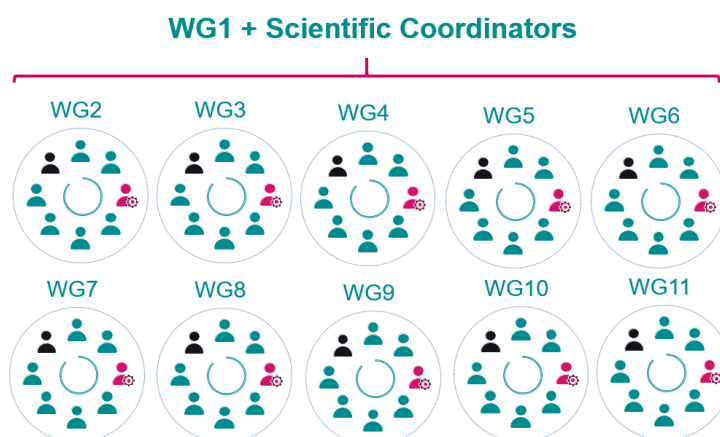
It is observed that configurations may be grouped around 3 different types according to the maturity of the genomics or the initiative in the country. These 'models' are:

- **'Small countries with National Genomics Strategy' model:** because of the size of the country and the internal organization 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 to the initiative.

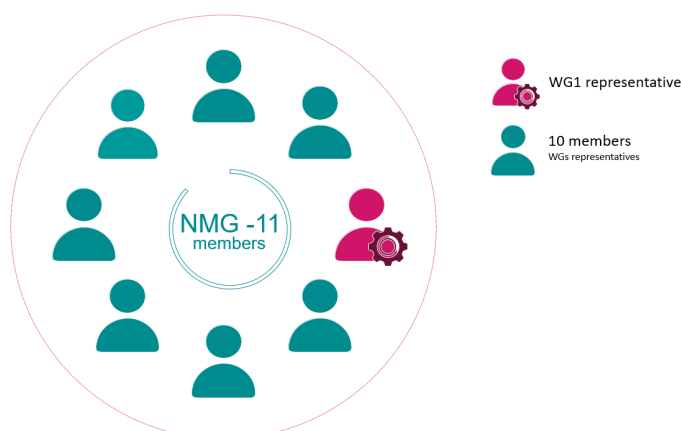




- **‘Big countries with National Health Service System’<sup>14</sup> model:** these countries have established NMGs for each WG of the initiative. These 11 NMGs are coordinated by the national representative of each WG in the initiative and each group is composed of between 5-7 experts.



- **‘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.



<sup>14</sup> The government provides free health care paid for with revenue from income taxes. Services are government owned and service providers are government employees. Every citizen has the same access to care.

It should be noted that two countries have a size of their NMGs greater than the rest (IT, ES), it is observed that this coincides with the fact that in 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 hand, we cannot ignore that these have been the two countries that have given their complete composition of NMGs and that other countries may be in the same case but may not have given their complete composition.

Regarding the representation of stakeholders, it should be noted that most of the countries have a high representation of the research and university communities and not so much of the clinics. There is also insufficient representation from patient organizations. The industry is only represented in half of the countries, although its engagement has increased compared to the first surveys carried out by the EC in early 2020.

Furthermore, no country has representation of all types of stakeholders in its NMGs.

## 7. Conclusions

After analyzing the results we can give the following recommendations:

**Profiles and contacts for the management of NMGs:** It is evident that it is necessary to define and clarify the profiles and contacts for the management of NMGs so that they are implemented by countries that do not yet have them.

**Stage in establishing NMGs:** To achieve the goal on NMGs approved in the initiative's roadmap, it is necessary that at least all countries throughout 2021 have their NMGs in a stage of 'Constructing/starting up' and that by the end of 2021 at least 75% of the countries have their NMGs operational.

**Establishment of NMGs:** It would be necessary to define 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.

**Engagement between NMGs and initiative:** It is necessary that all NMGs have a high 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. In addition, to achieve this, 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.

**Funding or specific assignment:** Ways should be sought through which the work of the NMGs is funded 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.





**Stakeholders' representation:** Countries should be encouraged to:

- Supplement their NMGs to have as much stakeholder representation as possible.
- The inclusion of patient organizations 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 provided healthcare.

## 8. Next steps

With these results (and with the help of the results that are yet to come from the countries that have not yet answered the survey) we will set up some guiding principles and identify best practices for the good set-up, running and coordination of mirror groups.

In addition, these initial results and conclusions will be presented to the 1+MG Commission Special Group as a policy brief to obtain the endorsement of the countries.

In the medium term, it will be monitored which of these models and practices that we have identified in this first policy briefs are confirmed as good practices and which are not.

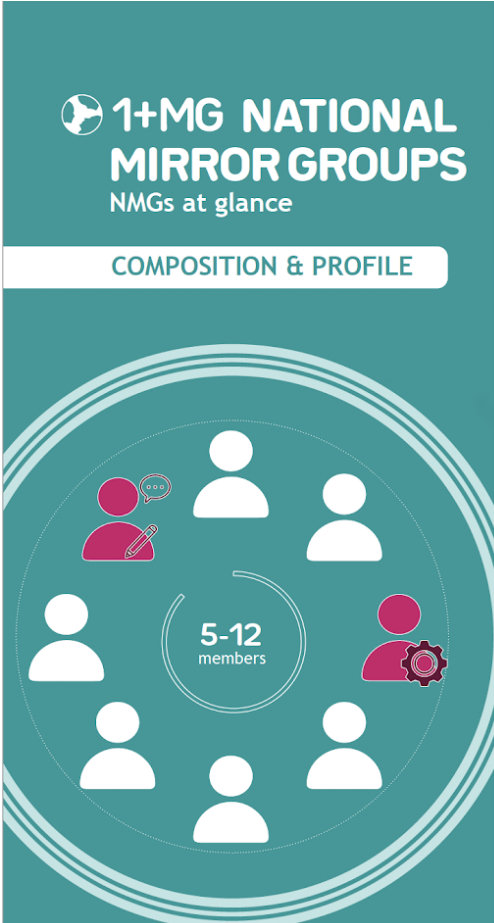
## 9. Impact

It is expected that, with this first approach to NMGs, the countries that have their NMGs configured will increase their engagement and improve their configuration and mode of operation and that those who have not yet configured their NMG will use this knowledge to establish them.









## 10. Annexes

### 10.1. Factsheet ‘National Mirror Groups at Glance’



**1+MG NATIONAL MIRROR GROUPS**  
NMGs at glance

**COMPOSITION & PROFILE**

-  **1 Scientific Coordinator**
-  **1 National Contact Point (NCP)**  
Nominated by each NMG, they work as interlocutors between the EC and their group.
-  **5-12 members**  
Depending on the configuration at the national level.
-  **Adequate gender balance**
-  **Wide geographical representation in each country**
-  **A diverse representation of stakeholders**  
Research/university/clinical/IT/data communities, ministry/agency/executive/policy maker, industry/private sector, ELSI, funding agencies, patient organisations.

The 1+MG National Mirror Groups (NMGs) feed their national experience into the 1+ Million Genomes Initiative.

These national instances will ensure the effective implementation of the roadmap at a national and local level by 2022.

**MISSION**

- Improve quality of life**  
*To improve EU citizens quality of life by enabling transnational access to genomics data*
- Facilitate access to the initiative's information**  
For national experts and policymakers to ensure the alignment of Member States with the initiative's objectives.
- Promote national adoption and sustainability**  
To ensure synergistic implementation in each National Health System and provide recommendations to local and European funders.

**ROLE**

- National contributors**  
The NMG experts will provide advice and support in implementing the initiative's objectives.  
\*It is expected that a representative of the NMGs, designated by the Member States, participates in the initiative's annual meetings and provides feedback on the outcomes of the B1MG project that support the initiative.
- Initiative multipliers**  
As national representatives, their role will also be to receive and transmit information to their national initiatives to encourage adoption.

**TASKS**

NMGs, alongside stakeholders, will create a space for dialogue to:

- Build a decision-making framework**  
For public-private participation and increased health literacy among stakeholders.
- Envision a future framework**  
For integrating emerging health technologies into health systems.
- Identify prospective mechanisms**  
For stakeholder cooperation – inside and outside the EU.

**About B1MG**  
Beyond One Million Genomes (B1MG) aims to create a network of genetic and clinical data across Europe by coordinating and supporting the implementation of the 1+MG Initiative. This initiative is a commitment of 21 European Member States and Norway to give cross-border access to one million sequenced genomes by 2022.

B1MG has received funding from the European Union's Horizon 2020 Research and Innovation Programme under grant agreement No 951724

**About this fact sheet**  
This fact sheet will evolve at the same rate as the initiative itself and the development of the NMGs.

## 10.2. National Mirror Groups Survey

### Questions regarding the development and organisation of National Mirror Groups (NMGs) in the framework of the 1+MG initiative

#### Introduction and background

The data you enter in the following sections will be used for the National Mirror Groups activities related to the execution of the H2020 B1MG project (EC Grant number: 951724) see <https://b1mg-project.eu/>.

The main goal of B1MG is to support the 1+MG initiative, including the definition of guidance for the 1+MG National Mirror Groups as part of WP6 activities lead by ISCIII.

The information that you will provide through this survey ( and via filling and returning the spreadsheet that you will find on the following pages ) will be used for the purposes described above and to improve communication across NMG, with the 1+MG Initiative, and with the B1MG project.

In accordance with the Grant Agreement, the data you will provide will be retained during the project and deleted when it has ended as soon as the retention period established by the EC is over.

By filling this form you agree that ELIXIR will store and process your data for the purpose indicated above.

If you would like to access, update or delete your personal data in the meantime, please contact us using [B1MG-Coordination@elixir-europe.org](mailto:B1MG-Coordination@elixir-europe.org)

Should you have any data protection queries, please address these to the coordination team ([b1mg-coordination@elixir-europe.org](mailto:b1mg-coordination@elixir-europe.org)) so that we may present them to the EMBL Data Protection Officer (DPO).

You can find the [ELIXIR Privacy Policy following this link](#)

#### Profile and contacts

\* Mandatory answers

\* 1. Country

\* 2. Representative of WG1

Name

Affiliation

e-mail address



**NOTE:** A representative designated to represent a Member State in the Governing Board of 1+MG (via Working Group 1).

\* 3. NMG Scientific Coordinator (If you do not have a figure as Scientific Coordinator or it is the same person as WG1 representative please put N/A or SAME)

Name	
Affiliation	
e-mail address	

**NOTE:** The NMGs Scientific Coordinator is the person in charge of managing the nominations and validations of scientific experts to take part in the NMG of your country.

\* 4. National Contact Point of NMG (If you do not have a figure as NCP or it is the same person as WG1 representative or Scientific Coordinator please put N/A or SAME)

Name	
Affiliation	
e-mail address	

**NOTE:** The National Contact Point for an NMG is the person in charge of managing the internal communication within the NMG.

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

## National Health Genomics Plan

\* Mandatory answers

\* 6. Do you have a National Health Genomics Plan?

☐ Yes

☐ No

7. Webpage (link) of the plan:



8. Contact person in your country for the plan:

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

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

## National 1+MG Roadmap

\* Mandatory answers

\* 10. Do you have a roadmap related to the 1+MG initiative in your country?

☐ Yes

☐ No

11. How will the 1+MG initiative's roadmap be implemented in your country? Please provide a brief explanation or additional public information (e.g. report, website) if available.

## National Mirror Groups composition and functioning

\* Mandatory answers

\* 12. At what stage is your country in establishing a 1+MG National Mirror Group? Please select one of the following options.

- ☐ No tangible activities yet (No expert nominees for the NMGs yet)
- ☐ Planning/preparing (Not all NMGs exist but expert nominations begin)
- ☐ Constructing/starting up (Much of the nominated experts and governance structure beginning to be implemented)
- ☐ Operational (All groups with their nominated experts and with an operational governance structure)



\* 13. Please provide a short explanation to your answer:

\* 14. 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](mailto:B1MG-Coordination@elixir-europe.org) with the subject: "B1MG: NMG Composition < country >".

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

☐ Document has been sent

☐ Other (please specify)

\* 15. Expert nomination process to join the NMGs

\* 16. Communication process with and among NMGs (please describe how often NMG exchange information and/or meet)

\* 17. Governance structure in the NMGs

\* 18. Do you organize activities at national level with the NMG?

☐ Yes

☐ No

19. What kind of activities?

\* 20. Are the activities of the NMG funded in your country?

☐ Yes

☐ No

21. How?

\* 22. Does the NMG have a specific assignment from the government?

☐ Yes

☐ No

23. How is it financed?

\* 24. Is the NMG in your country formalised?

☐ Yes

☐ No

25. In which way?

### NMG links to the 1MG Initiative

\* Mandatory answers

\* 26. How active are NMG members in the initiative? (value the activity of NMGs between 1 and 5)

1 Not active	2	3	4	5 Very active
★	★	★	★	★

\* 27. Do you think there is sufficient links between NMG and the European Initiative?

☐ Yes

☐ No

28. If not, please describe how they would be further involved/engaged





[illegible]