



Beyond One Million Genomes

## D1.2 - Generation of a stakeholder portal within the project webpage containing the information resulting from the activities of the SCG

Project Title (grant agreement No)	Beyond One Million Genomes (B1MG) Grant Agreement 951724		
Project Acronym	B1MG		
WP No & Title	WP1 - Framework for Cooperation through Stakeholders Engagement, Awareness & Alignment		
WP Leaders	Denis Horgan (EAPM), Ruben Kok (DTL-Projects), Jan Korbel (EMBL Heidelberg), Toni Andreu (EATRIS).		
Deliverable Lead Beneficiary	8 - EATRIS		
Deliverable	D1.2 - Generation of a stakeholder portal within the project webpage containing the information resulting from the activities of the SCG		
Contractual delivery date	31/05/2021	Actual delivery date	26/05/2021
Delayed	No		
Authors	Emanuela Oldoni (EATRIS), Toni Andreu (EATRIS),		
Contributors	Merlijn van Rijswijk (DTL-Projects), Ruben Kok (DTL-Projects), Xenia Perez Sitja (ELIXIR Hub), Nikki Couatts ELIXIR Hub) Juan Arenas (ELIXIR Hub)		
Acknowledgements (not grant participants)			



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

**B1MG**

Deliverable type	Report
Dissemination level	Public

## Document History

Date	Mvm	Who	Description
13/04/2021	0v1	Emanuela Oldoni (EATRIS)	[Initial draft circulated to WP participants for feedback]
13/05/2021	0v2	Nikki Coutts (ELIXIR Hub)	Version circulated to B1MG-OG, B1MG-GB & Stakeholders for feedback
25/05/2021	0v3	Emanuela Oldoni (EATRIS)	Final version with comments addressed
26/05/2021	1v0	Nikki Coutts (ELIXIR Hub)	Final version uploaded to the EC Portal and published in Zenodo

## Table of Contents

### [1. Executive Summary](#)

### [2. Contribution towards project objectives](#)

### [3. Methods](#)

### [4. Description of work accomplished](#)

#### [4.1 Main features of the Stakeholder portal](#)

##### [4.1.1 Facilitate community participation and engagement](#)

##### [4.1.2 Facilitate communication and collaboration](#)

##### [4.1.3 Facilitate documents sharing and management](#)

#### [4.2 How the Stakeholder portal looks like](#)

### [5. Results](#)

### [6. Discussion and Conclusions](#)

### [8. Next steps](#)

### [9. Impact](#)

## 1. Executive Summary

The B1MG stakeholder coordination portal aims to efficiently deliver timely analysis of challenges, opportunities and solutions resulting from external stakeholders to the operational



WPs. Developed by WP1 in close relationship with the communication and coordination teams (WP6), it delivers tools and defines workflows to de-risk and improve the flow of data generation and integration towards patients. These tools will help reduce cross-border barriers, and facilitate the development of operational pipelines based on the integration of genomic and health data.

The stakeholder portal allows the users to share contact information and develop a network within the B1MG project. People are organised in groups that reflect the stakeholder clusters with the possibility of users to create transversal sub-communities. The portal functionalities facilitate community participation and engagement, communication and collaboration and documents sharing and management. This allows the creation of a vibrant community, organised and focused, that can collaborate in an effective and advantageous way for improving the project outcomes.

## 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
<p><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</p>	
<p>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.</p>	<p>Yes</p>
<p>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.</p>	<p>Yes</p>
<p>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 &amp; M30.</p>	<p>N/A</p>
<p>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).</p>	<p>N/A</p>
<p><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</p>	
<p><b>Legal &amp; Ethical Key Results</b></p>	



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.	N/A
5: Long-term sustainability design and funding routes for cross-border Personalised Medicine delivery (WP6) by M34.	N/A

### 3. Methods

The implementation of innovation-driven healthcare in the genomic era requires stakeholders to take on a new, active role in decisions related to their health and that of society more broadly. The value chain for the use of genomic data into clinical decision making represents a strong



operational challenge, not only for the integration and FAIRification processes at early stages during data generation, but during the entire translational value chain. This process involves various stakeholders, such as academics, industry, policy makers, clinicians, whose success can only occur through structural and cross-sectional collaboration. In the specific case of the B1MG project, the translational process is even more challenging due to the multinational nature of the initiative.

In order to implement a way to ensure stakeholder involvement in the initiative and to bridge external stakeholders and operational Work Packages (WPs), WP1 in close relationship with the communication and coordination teams (WP6 - task 6.4) developed the Stakeholders portal. The stakeholder portal aims to efficiently deliver timely analysis of challenges, opportunities and solutions resulting from the external stakeholder to the operational WPs. The idea is that the Portal has to act as the main forum for discussion with stakeholders on a regular basis. Through the portal, stakeholder perspectives will be brought to the technical WPs in charge of creating the genomic translational pipeline. A specific domain in the B1MG project webpage ([www.b1mg-project.eu](http://www.b1mg-project.eu)<sup>1</sup>) allows access to the portal, possible upon registration. Applications are reviewed by WP1 and after approval the applicant receives an email notification and the portal access is granted. Main inclusion criteria are that the contribution and added value that the stakeholder can bring to B1MG and the fact that he/she belongs to one of the following groups, described extensively in D1.1:

- Citizens and patient organisations
- Clinicians, medical specialists
- Academics
- Medicines authorities (EU/EMA and national level)
- HTA bodies
- Funders
- Industry (diagnostic, pharmaceutical, ICT)
- National policy/decision makers
- Infrastructures
- EU Joint Actions

The portal has been developed using Google Sites, a structured wiki- and web page-creation tool included as part of the free, web-based Google Docs Editors suite offered by Google.

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<sup>1</sup><http://www.b1mg-project.eu>



The address is <https://sites.google.com/ebi.ac.uk/b1mg-stakeholders-portal/home><sup>2</sup>

The original title of this deliverable was “D1.2 - Generation of a stakeholder portal within the project webpage containing the information resulting from the activities of the SCG”. However, in the meantime the B1MG consortium in consultation with the EC has decided that a stakeholder coordination group (SCG) is no longer the preferred means for reaching the objectives of the 1+MG consortium. This will be explained in more detail in D1.1. which will be submitted in June 2021. Therefore this deliverable does not provide information around the SCG activities, as this has never been established.

## 4. Description of work accomplished

### 4.1 Main features of the Stakeholder portal

The Stakeholder Portal meets the following requirements:

- Facilitate community participation and engagement
- Facilitate communication and collaboration
- Facilitate documents sharing and management

#### 4.1.1 Facilitate community participation and engagement

The Stakeholder Portal allows the users to virtually meet and develop a network within the B1MG project. This allows the creation of a vibrant community, organised and focused, that can collaborate in an effective and advantageous way. People are organised in groups that reflect the stakeholder clusters with the possibility of users to create transversal sub-communities supported by specific communications channels that provide access to a set of additional functionalities.

#### 4.1.2 Facilitate communication and collaboration

In order to facilitate the communication and collaboration between users, the stakeholder portal has been developed with the following features:

- discussion forum capability with secure access to allow information sharing;
- tools that enable meetings, instant messaging, chat as space for dialogue;
- the ability of authorised users to create virtual workspaces that enable to share files and documents (Reports, TC minutes...);
- the possibility to integrate platform for video and audio conferencing for virtual meetings;

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<sup>2</sup><https://sites.google.com/ebi.ac.uk/b1mg-stakeholders-portal/home>



- full use of Outlook functions for emails, calendar and tasks for sharing relevant events for the project;

In the Stakeholder portal, the communications channels section is divided in different workspaces for specific purposes, called rooms. Rooms provide a shared view into the work being done. With access to the same information, everyone in the channel can work in lockstep, and new members have full context when they join. While working in channels, conversations and files become a searchable archive that gets more useful with time.

The Stakeholder Portal has been released with a limited set of the functionalities described above that will be extended as and when needed according to the utilisation and needs of the stakeholders. Additional details of the stakeholders portal can be found in D6.3 Communication strategy and in D6.2 Project Data Management Plan.

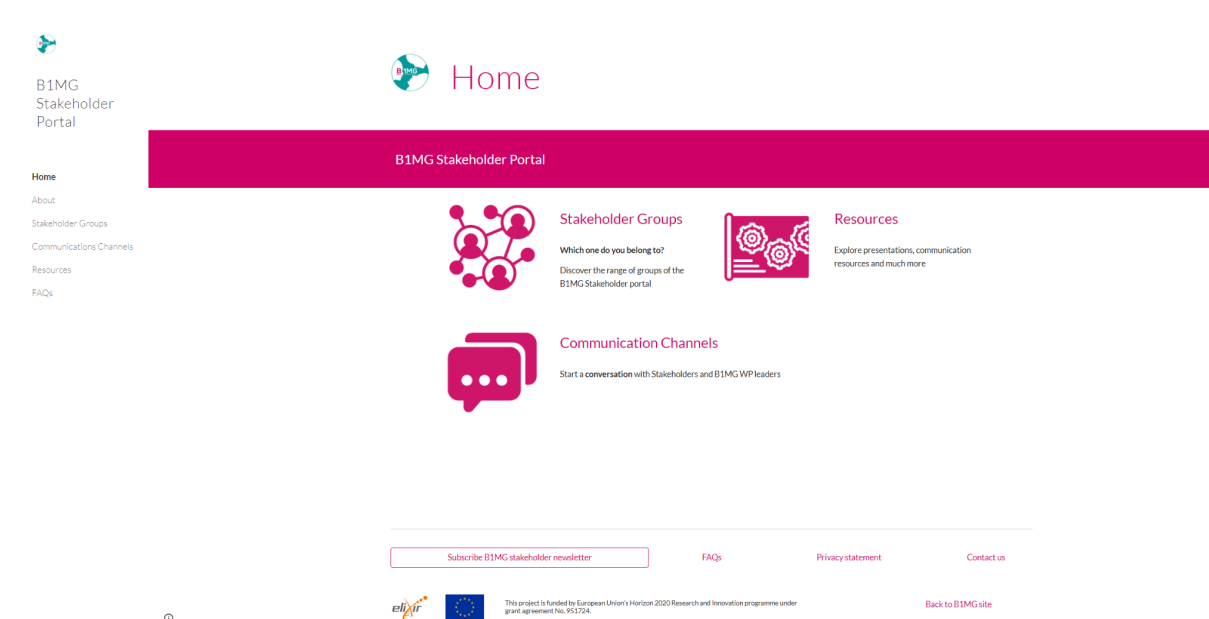
### 4.1.3 Facilitate documents sharing and management

The Stakeholder Portal is provided with a space for documents storage. This allows authorised users to easily have access to relevant documents and contribute to them. This space can be used as a repository for different types of documents, such as deliverable, meeting agendas and minutes, working documents and reports. WP leaders are in charge of populating the repository and of asking for feedback to relevant stakeholders.

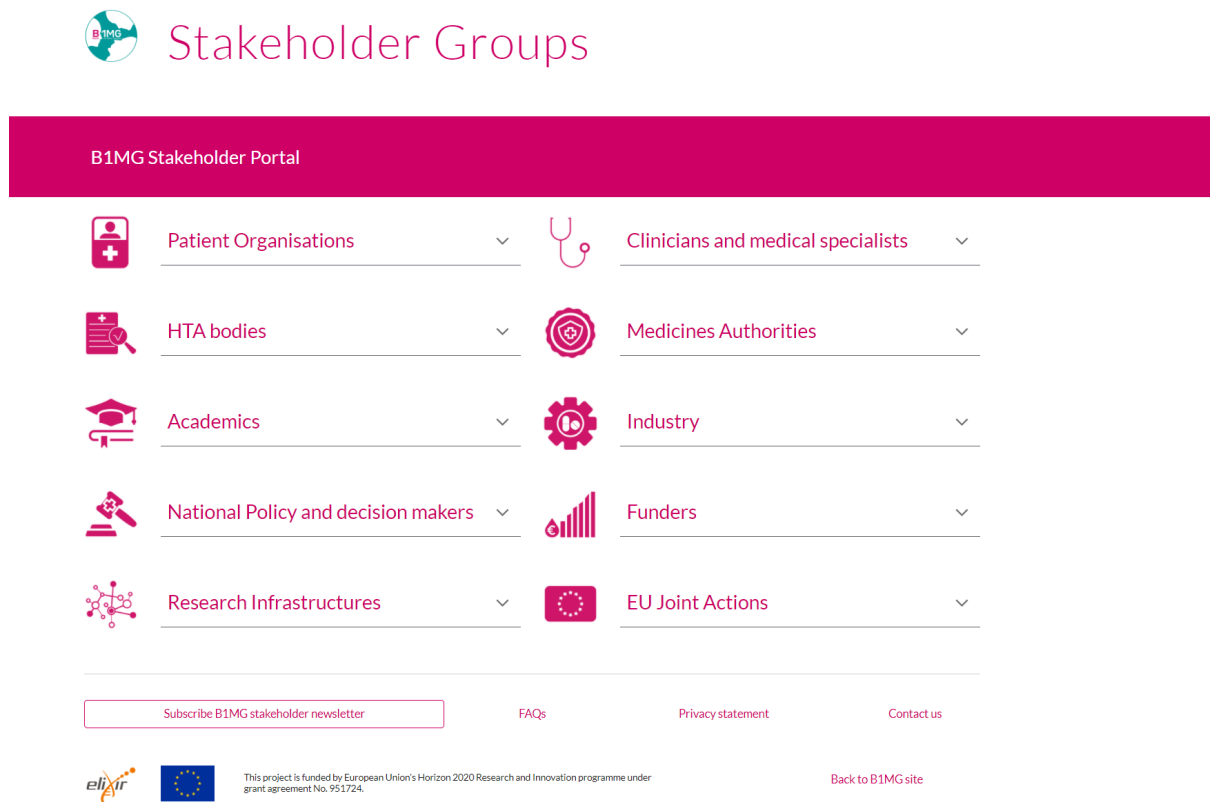
## 4.2 How the Stakeholder portal looks like

The Stakeholder Portal acts as a bridge where outputs of the projects can be shared with external stakeholders not directly involved in the project activities to gather additional feedback that will facilitate wider adoption of the project recommendations and guidelines. Screenshots of the stakeholder portal are provided below:

**Fig.1** Homepage



**Fig.2** Stakeholder groups



**Fig.3** Document repository





# Resources

**B1MG Stakeholder Portal**

TITLE	LAST MODIFIED
20200604 Kick-Off meeting slides	10/11/2020 Juan Arenas
20201215 1st review meeting report & slides	15/12/2020 Juan Arenas
Communication resources	11/11/2020 Juan Arenas
ELSI	2 Mar regina becker
NMGs	11/11/2020 Juan Arenas

- [Subscribe B1MG stakeholder newsletter](#)
- [FAQs](#)
- [Privacy statement](#)
- [Contact us](#)

**Fig.4** Communication channels

The screenshot displays a Microsoft Teams chat window for the 'b1mg-sp-academics' room. On the left, there is a sidebar with a 'Chat' section showing 'No conversations' and a 'Rooms' section listing several rooms, with 'b1mg-sp-academics' selected. The main chat area shows a search bar and a list of messages. The messages include:
 

- Nikki Coutts created this room on Friday, 22 Jan.
- Buttons for 'Share a file' and 'Assign tasks'.
- A 'HISTORY IS ON' notification: 'Messages sent with the history turned on are saved'.
- Nikki Coutts added Juan Arenas.
- Nikki Coutts invited Emanuel Oldoni.
- Nikki Coutts invited damjana.rozman1@gmail.com, ine.vanhoyweghen@kuleuven.be, Fotis Psomopoulos, Victoria D Bohler, Naira Naouar + 2 more.
- Nikki Coutts added Jennifer Harrow, Gary Saunders.
- Nikki Coutts invited damjana.rozman1@gmail.com, alja.videtic@mf.uni-lj.si, mbyescolomer@gmail.com, susannerebers@gmail.com, tadeja.rezen@gmail.com + 10 more.
- Nikki Coutts invited Toomas Veidebaum, mario.gaspar.silva@edu.ulisboa.pt, Maldo Remm, margherita.mutarelli@gmail.com, petra.hudler@mf.uni-lj.si + 7 more.
- Hana Svozilová, Fotis Psomopoulos, Heidi Beate Bentzen, andres.metspalu@ut.ee, Till Andlauer, Naira Naouar, Emanuela Oldoni, Maldo Remm, Michael Crusoe, Patrick Kemmeren joined.

 At the bottom, there is a notification setting bar for 'b1mg-sp-academics' with options 'Notify always', '@mentions only', and 'Don't notify'. A 'History is on' indicator is also present at the very bottom of the chat area.



## 5. Results

The portal was launched in October 2020, during the Stakeholders Forum Meeting, and in April 2021 counted 146 stakeholders, classified as reported in table 1 and in figure 5.

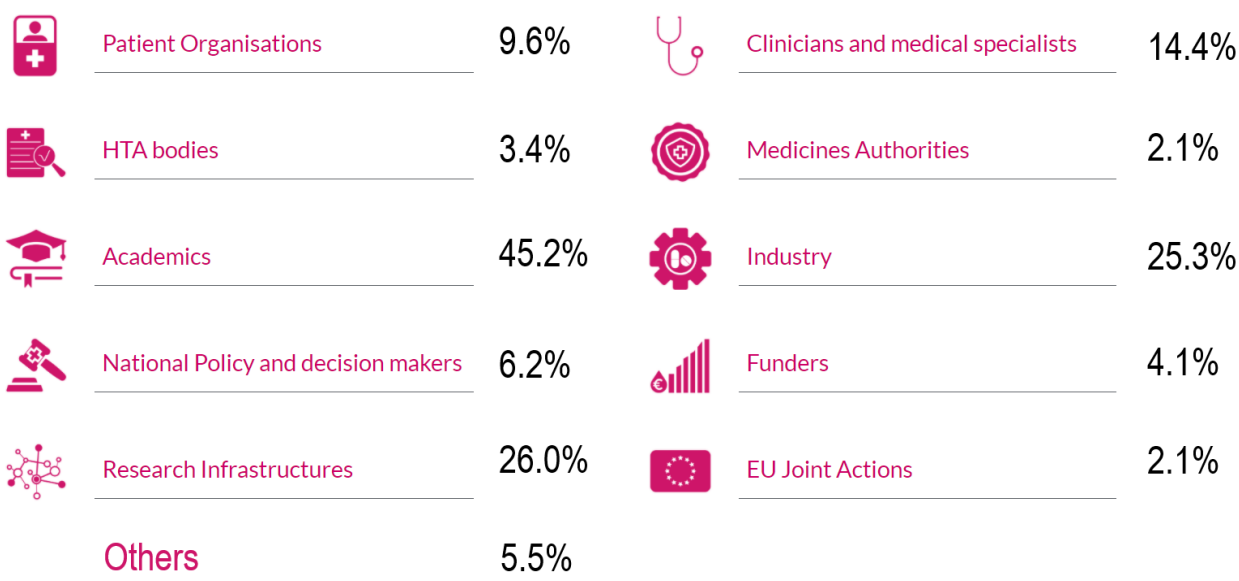
**Table 1.** Detailed overview of stakeholders registered to the portal on April 13th 2021

<b>Stakeholders group</b>	<b>N</b>
Academics	31
Academics, Data providers	1
Academics, ELSI / research	1
Academics, Industry (Diagnostic, Pharmaceutical, ICT)	1
Academics, Industry (Diagnostic, Pharmaceutical, ICT), Infrastructures	1
Academics, Infrastructures	11
Academics, Infrastructures, EU Joint Actions	1
Academics, Infrastructures, informatics/standards/clinical data	1
Academics, National Policy/Decision Makers, Infrastructures,	1
Academics, Other - please specify, EU H2020 INTERVENE project	1
Clinicians, medical specialists	5
Clinicians, medical specialists, Academics	11
Clinicians, medical specialists, Academics, National Policy/Decision Makers	1
Clinicians, medical specialists, Industry (Diagnostic, Pharmaceutical, ICT)	1
Clinicians, medical specialists, Other - please specify, Representative of The Family Physicians Association of Estonia	1
Funders, Industry (Diagnostic, Pharmaceutical, ICT), Infrastructures	1
Funders, National Policy/Decision Makers	2
HTA bodies	2
HTA bodies, Funders	1
Industry (Diagnostic, Pharmaceutical, ICT)	26
Industry (Diagnostic, Pharmaceutical, ICT), Infrastructures	4
Infrastructures	16
Infrastructures, Clinical Genomics Software	1



Laboratory scientists	1
Medicines authorities (EU/EMA and national level)	1
National Policy/Decision Makers	4
National Policy/Decision Makers, Regional policy advisor	1
Patient organisations	11
Patient organisations, Academics, bid writing	1
Patient organisations, Clinicians, medical specialists, Academics, Medicines authorities (EU/EMA and national level), HTA bodies, Funders, Industry (Diagnostic, Pharmaceutical, ICT), National Policy/Decision Makers, Infrastructures, EU Joint Actions	1
Patient organisations, Clinicians, medical specialists, Academics, Medicines authorities (EU/EMA and national level), HTA bodies, Funders, Industry (Diagnostic, Pharmaceutical, ICT), National Policy/Decision Makers, Infrastructures, EU Joint Actions, Other - please specify	1
Representation of university medical centres	1
Others	1

**Fig.5** Percentage of breakdown of members registered in April 2021:



On **February 18 at 14:00-15:00 CET**, WP1 and WP6 organized a **virtual webinar focusing on everything you need to know about the Stakeholders Forum portal** ([presentation here](#)). 42 participants among stakeholders and WP leaders attended the webinar, whose recording is available on the portal. Stakeholders and WP leaders have been invited to actively build the portal together with WP1 and WP6 according to their needs. In addition, after the webinar, WPs

leaders have been engaged via email and encouraged to have an open dialogue with the stakeholders, through the portal.

## 6. Discussion and Conclusions

WP1 aims to implement a systematic way to drive stakeholder involvement, taking into account the need to coordinate between scientific and technical communities, as well as national healthcare systems. This WP is working to ensure that the consortium actively engages with relevant external stakeholders, projects and initiatives at a pan-European level, and that the B1MG initiative not only gains maximum visibility, but also benefits from the mutual exchange between external stakeholders and operational WPs.

With this scope and thanks to the close collaboration between WP1 and WP6, it was possible to develop and launch the stakeholders portal months in advance than the expected date in the WP description. This allowed a stakeholders engagement in the early stages of the projects and created a community with more than 100 experts and representatives of various groups that started to work together with technical WPs in charge of creating the genomic translational pipeline.

Academics, industry and research infrastructures representatives cover a large chunk of this community, followed by clinicians and patient organisations. Patient organisation involvement is key as it brings patients' perspective on B1MG operations and supports the public trust building more broadly. Although in a smaller percentage, the project benefits from HTA bodies, policy makers and medicine authorities' perspectives.

Building the stakeholder portal was a relatively straightforward task, but ensuring that it is integrated into the operational WPs workflows and that the stakeholders will provide inputs is the real challenge. Structural and cross-sectional collaboration of various stakeholders is needed and in the specific case of the B1MG project, this task is challenging due to the multinational nature of the initiative. Commitment, participation and active presence of stakeholders and B1MG operational WPs are fundamental for the success of this project and they must maintain a high level of engagement through the portal and use this tool to further structure their dialogue. For raising awareness around this key point and for officially presenting the portal to the users, On February 18, WP1 and WP6 organized a virtual webinar focusing on everything you need to know about the Stakeholders Forum portal. 42 participants, among stakeholders and WP leaders, joined the webinar and actively participated. After presenting the main functionalities of the tool, in the Q&A session it has been discussed how the portal further develops. In fact, the stakeholder portal is born as a living platform that can be re-shape according to the needs of the user community. Improvement and implementation are foreseen in the future in order to provide both stakeholders and the B1MG consortium with an efficient and useful space where working together.

## 8. Next steps

- Engagement with stakeholders and WP leaders for encourage the actual use of the portal



- Looking at the process of stakeholder partner projects, identification of new needs portal-related in the perspective of a growing Stakeholder Forum

## 9. Impact

Through the portal, the B1MG consortium maintains a high level of engagement with the European healthcare ecosystem, implementing personalised medicine. The portal is an important operational tool and retrieves feedback to the Member States, including inputs from global organisations working on implementational strategies for genomic medicine and Personalised Medicine. Through the Stakeholder portal we are building a community that will contribute to a global co-creation process and will make the objective of 1+MG initiative a reality.

