

945345 – H2O

Health Outcomes Observatory

WP1 – Governance-Sustainability-Capabilities

## D1.3 Bylaws of the Patient Advisory Boards

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## Definitions

- **Participants** of the H2O Consortium are referred to herein according to the following codes:
  1. **MUW.** Medizinische Universitaet Wien
  2. **Charité.** Charite – Universitaetmedizin Berlin
  3. **EMC.** Erasmus Universitair Medisch Centrum Rotterdam
  4. **ICS-HUVH.** Institut Catala De La Salut – Hospital Universitari Vall d’Hebron
  5. **KCL.** King’s College London
  6. **KUL.** Katholieke Universiteit Leuven
  7. **EPF.** Form Europeen des Patients / European Patients’ Forum
  8. **I-HD.** The European Institute for Innovation through Health Data
  9. **The Hyve.** The Hyve BV
  10. **TEAMIT.** TEAM IT Research SL
  11. **KUH.** Karolinska Universitetssjukhuset
  12. **UniSR.** Universita Vita-Salute San Raffaele
  13. **IKNL.** De Stichting Integraal Kankercentrum Nederland
  14. **TAKEDA.** Takeda Pharmaceuticals International AG
  15. **NVS.** Novartis Pharma AG
  16. **ABBVIE.** AbbVie INC
  17. **Lilly.** Ali Lilly and Company Limited
  18. **MDT.** Medtronic International Trading SARL
  19. **Pfizer.** Pfizer Limited
  20. **ROCHE.** F. Hoffman-La Roche Limited
  21. **SARD.** Sanofi-Aventis Recherche & Development
  22. **JDRF.** JDRF International
  23. **Trial Nation.** Trial Nation
  
- **Grant Agreement.** (Including its annexes and any amendments) The agreement signed between the beneficiaries of the action and the IMI2 JU for the undertaking of the H2O project (Grant Agreement No. 945345).
- **Project.** The sum of all activities carried out in the framework of the Grant Agreement.
- **Consortium.** The H2O Consortium, comprising the above-mentioned legal entities.
- **Consortium Agreement.** Agreement concluded amongst H2O participants for the implementation of the Grant Agreement. The agreement shall not affect the parties’ obligations to the Community and/or to one another arising from the Grant Agreement.



*Figure 1. H2O official logo.*

## Abbreviations

Acronym / Abbreviation	Meaning/Explanation
AC	Associated Collaborators
CC	Country Coordinators
EMA	European Medicines Agency
T1DM	Type 1 Diabetes Mellitus
T2DM	Type 2 Diabetes Mellitus
H2O	Health Outcomes Observatories
PROMs	Patient Reported Outcome Measures
PREMs	Patient Reported Experience Measures
IBD	Inflammatory Bowel Disease
IM	Induction Meeting for the PABs
GA	General Assembly
IMI	Innovative Medicines Initiative
IMI2 JU	Innovative Medicines Initiative Programme 2 Joint Undertaking
KPI	Key Performance Indicator
PL	Project Leader
PROs	Patient-Reported Outcomes
WP	Work Package

## Abstract

H2O is a strategic partnership between the public and private sectors to create a robust data governance and infrastructure model to collect and incorporate patient outcomes at scale into healthcare decision making at an individual and population level. It aims to support better health outcomes by creating and implementing an unprecedented, standardised data governance and infrastructure system across Europe to incorporate patients' experiences and preferences in decisions affecting their health care. The public and private sectors have partnered to launch the H2O project to deliver a positive impact across the health care ecosystem by enhancing health research prospects, promoting the development of new treatments that reflect outcomes reported by patients and sustaining more efficient healthcare systems.

The aim of deliverable D1.3 - Bylaws of the Patient Advisory Boards - is to lay the foundation of patient involvement in H2O project, set the terms of reference and recommend principles for the selection and engagement of patients and patient representatives in the three disease-specific Patient Advisory Boards (PABs). Furthermore, this deliverable will present the most important operational and governing sides of the three boards within the disease-specific work packages, propose potential activities and timelines, and finally, highlight good practices for patient co-creation across all relevant aspects of the H2O project's activities.

## 1. Introduction

H2O is a strategic partnership between the public and private sectors to create a robust data governance and infrastructure model to collect and incorporate patient outcomes at scale into healthcare decision making at an individual and population level. The H2O approach gives patients ultimate control of their health data and ensures that only they exercise this control. Patient control and consent over access to health data is one of the key topics in the community today, perhaps even the most important topic and H2O will set the standard in terms of governance for patients being data donors. The objectives of deliverable 1.3 is to set the main governance and operational framework under which patients and patient representatives will be involved in H2O project. For this purpose, three disease-specific Patient Advisory Boards (PABs) will be established. This deliverable is also the backbone of the collaboration between patients/patient representatives/advocates and EPF and other H2O consortium partners. The core PABs activities and commitments during the life span of H2O project are based on the principles placed in this deliverable, however, additional tasks will occur when the three PABs are set up in M7, gather for the Induction Meeting (IM) and undergo their functions.

### 1.1. About H2O

Patients' outcomes and experience of healthcare can be improved through the systematic capture and use of information from their perspective. Today, the full potential of information gathered from patients' outcomes and experience of healthcare is not fully utilized, and this is due to lack of standardisation, interoperability, and implementation of Patient Reported Outcome Measures (PROMs) schemes. Furthermore, the processes can still be improved through systematic capture and use of information from patients' perspectives. There is an urgent need for a European scale network of outcomes data collection, analysis and data-sharing to inform clinical practice, evidence-based advocacy and healthcare decisions. To tackle all these issues and challenges, the H2O public-private consortium brings together scientists, clinicians, and professionals to design and set up independent, patient-centred, Health Outcomes Observatories (H2Os). These Observatories will collect the data provided through meaningful involvement of patients, providers, and health care decision makers (health ministries, health insurers, regional health authorities, public health agencies, medicines regulators, health technology assessment agencies). The service will not only inform care at individual patient level, but, once the data is anonymised and aggregated, it will generate valuable information: 1. for patients' choices on their individual clinical care, 2. to facilitate evidence-based advocacy of patient groups on the quality and effectiveness of health technologies; 3. for the evaluation of new technologies and for healthcare decision-making. Based on a hybrid model of federated and centralised data collection, management and analysis, these Observatories will operate under a governance model that will guarantee that data are protected under jurisdictional data protection law.

### 1.2. H2O Consortium – in a nutshell

The project consortium consists of 23 partners, representing numerous stakeholder views and perspectives. H2O brings together representatives from patients' associations, clinicians, industry, researchers, and health authorities to build a European scale network of outcomes data collection,

analysis and evidence sharing to inform clinical practice and healthcare decisions. This public-private alliance is set to take the prominence of health data outcomes in clinical care, health research and healthcare systems to the next level. Health Observatories will be connected to a pan-European umbrella H2O to facilitate interoperability, guide reproducibility in other countries, and promote the benefit of measuring and using patient-centred outcomes at regional, national, European, and international levels.

### 1.3. About EPF, WP1 and task 1.5

EPF is an umbrella patient organisation that works with patients' groups in public health and health advocacy across Europe. EPF members represent specific chronic disease groups at EU level or are national coalitions of patient organisations which represent different chronic conditions. Through consultations with a diverse membership across Europe, EPF gathers patients' views and channels their voice to inform decision making in public health, health-related research and in the definition of innovative patterns for patient involvement. EPF, with the support of project partners of the H2O consortium, will create and coordinate the **three disease-specific PABs** - entities that will be the main gatekeepers when it comes to patient engagement and patient involvement in H2O project. The main roles and responsibilities of PABs members are defined below in this deliverable in the respective sections.

**Work Package 1 (WP1)** is strictly focused on the governance, sustainability and capabilities of the project. It is central to the H2O project because it will define the core concepts, but also it aims at achieving the following specific objectives, according to the H2O Grant Agreement:

- It will ensure the ability of the Observatories to collect new data and make them interoperable with existing health data sources in the respective countries, in the best interest of patients, science and society.
- It will define the governance and legal framework, business architecture and quality assurance processes to ensure that the H2O ecosystem of the Tier One national Observatories and the pan-European Observatory have been designed in a way to empower patients to monitor their outcomes, create transparency of outcomes within the ecosystem and ensure long term sustainability of the organisations.
- It will ensure compliance with European and each country's legal and policy stipulations regarding the collection, use and sharing of health outcomes data, including data protection, whilst balancing the needs for national specificity with the greater value and scalability from adopting common European governance models and legal frameworks, architectures, interoperability and outcomes standards.
- It will engage stakeholders to maximise the value for all involved parties, so that the increasing capture of health outcomes information leads to benefits for individual patients while growing collective insight into the extent of outcomes currently achieved and how to improve them, by increasing the evidence in favour of value-based care models.
- It will ensure the engagement of patient organisations and individual patients across the H2O work plan to ensure patient perspectives are incorporated at all strategic and user levels.
- It will define KPIs for the project and for the final H2O ecosystem, will monitor progress towards their achievement and publish regularly reports to socialize learnings.

- It will define and promote sustainable business models at national and above country levels, to be taken up by WP6, with the aim of designing an environment in which additional countries and disease areas can easily be added later.

Within WP1, EPF is undertaking **Task 1.5** which provides the framework for selecting, recruiting, training and engaging patients and patient representatives in three disease-specific PABs. Furthermore, EPF needs to ensure their smooth functioning, especially on the outcomes and metrics that are of value to patients and the patient community overall. These PABs are designed to bring diverse knowledge and expertise to the H2O project and meaningfully embed the patient perspective into key outputs of the project.

These PABs, in their advisor capacity, will be working closely with EPF and other appointed consortium partners from across various WPs.

#### 1.4. What is a Patient Advisory Board (PAB) in H2O and who is part of it?

A Patient Advisory Board in H2O project is an entity which is deeply embedded within the project in order to promote active and meaningful participation from patients and patient representatives across the project's to co-create activities, tasks, and deliverables. The idea is to build on the PABs knowledge and expertise on project related topics and areas to ensure patients views are fully captured and implemented. Given the importance of putting patients at the centre of care and research, the PAB will play a crucial role for the success of the project. Each Board will be composed of patients and/or patient representatives in the field of the three project-related disease areas (diabetes, IBD and cancer). PABs members will be invited to attend project related meetings and advise on key documents and deliverables not only of the three disease areas/WPs, but also across other work packages/tasks/activities in H2O, however, EPF and JDRF will have to oversee and manage this process, especially when it comes to the PABs capacity and resources. Furthermore, representatives of national coalitions of patient organisations in Europe are invited to join the three PABs as well and bring the national/regional perspective. The Boards will give advice on the development of governance, technology, and reporting, as well as PROMs selection in direct interaction with the disease-specific work packages. Therefore, participants will also be selected from patient organisations active at European and national/regional level and EPF will be leading on this process. See *graph 1* for more information on the PABs composition and Annex III for the key organisations already approached by EPF since the kick-off of H2O project.

As a task leader, EPF must provide the framework for selecting, recruiting, training and engaging patients for disease-specific PABs, and ensure their smooth running, especially on the outcomes and metrics that are of value to patients. Furthermore, PABs will be designed to bring diverse knowledge and expertise. Therefore, participants will be selected from patient organisations active at the European and national/regional level.

## 1.5. Mission of the PABs

Patient Advisory Boards will give voice to the experiences, opinions and desires of patients, patient representatives and potentially their relatives (indirectly) to help ensure that H2O project goals and strategy are fully aligned with the goals of people living with and affected by the respective diseases tackled by the Project – T1DM, T2DM, IBD and four types of cancer (Breast Cancer, Lung Cancer, Multiple Myeloma and Non-Hodgkin Lymphoma).

By bringing a powerful patient perspective to H2O, the PABs will help ensure the project will deliver a patient-centric approach and specific outcomes with the potential to improve the lives of people with the three disease areas described earlier.

Lastly, PABs' activities will also support patient empowerment and patient involvement in the development and implementation of H2O core principles, tasks, and objectives.

## 1.6. PAB Structure and Function

### 1.6.1 Structure

Each disease specific Board will consist of eight **(8) patients and/or patient representatives** each, respectively divided in the following way:

- One from each national disease specific patient organisations from the H2O countries (Austria, Germany, Spain, and the Netherlands)
- One from a national coalition of patient organisations
- One from a European level disease specific platforms/organisations
- One from an additional country (so far, the agreement is representatives from Belgium, Denmark and/or UK to be invited)
- One from Central- Eastern Europe to ensure an inclusive engagement and better capture the perspective of patients from different geographies.

# H2O Patient Advisory Boards



Graph 1

There will be no hierarchical structure and all members will have the same rights and responsibilities across the three PABs.

## 1.6.2 Quorums and Voting Rights of the PABs members

Each member of the three PABs will have equal rights and responsibilities. There will be no hierarchical structure and all 24 patients and/or patient representatives in the three Boards will have the same voting rights and ranks. When it comes to decision-making the principle of simple majority 50 + 1 % will be applied.

The percentage of PABs members needed to be present during these sessions/events to achieve quorums is again based on the principle of simple majority: 50 + 1 %.

As each member of the PABs will have equal rights and responsibilities and it is expected that all PABs members will have diverse backgrounds and set of expertise, in order to achieve a division of tasks, depending on the profiles and interests of PABs members.

This section relates to the PABs meetings and does not extend to other parts of H2O project.

## 1.6.3 Meetings

There will be two main types of meetings that members of the PABs are expected to attend and meaningfully and actively contribute to:

- Regular bi-monthly meetings – these will take place online and T1.5 co-leads EPF and JDRF will lead them. It is expected to have six (6) online meetings per year. EPF reserves the right to request help from other project partners across the Project when these meetings tackle matters from the respective disease-specific WPs.
- Five Annual Workshops (online or face-to-face, depending on the travel restrictions in Europe) – during these workshops, EPF and JDRF will oversee the overall structure, agenda, note taking, next steps. etc.
- The workshops might last one full day or several shorter online sessions. Timing will be decided during the induction meeting in M7 (see sections 1.6.6 and 1.8. for more information).

In addition, a third type of meetings can occur upon requests from H2O partners:

- Ad-hoc meetings with H2O partners on specific topics or activities related to the project.

### 1.6.4 Reporting

There are several types of reports following the online bi-monthly meetings and annual workshops:

- Minutes (always ending with to-do-lists/action points/next steps) after each bi-monthly online meeting, saved and shared among the three PABs
- Annual Workshop minutes, saved and shared among the three PABs and H2O partners
- Bi-yearly overviews for external audiences shared with the H2O Comms team

More on reporting can be found in section 1.6.6.

### 1.6.5 Expectations – a two-way street

In order to achieve successful operating of the PABs and meaningful patient engagement in H2O, expectations on both ends (members of PABs and T1.5/H2O partners) should be sensible and agreed goals should always follow the SMART criteria:

**Specific** – target a specific area for improvement.

**Measurable** – quantify or at least suggest an indicator of progress.

**Assignable** – specify who will do it.

**Realistic** – state what results can realistically be achieved, given available resources.

**Time-related** – specify when the result(s) can be achieved.

Members of the PABs should be acting as ambassadors and champions for the project. They will be participating in key task forces and committees, “leading by example” and helping patients outside the three Boards in order to ensure acceptance and sustainability. They will give advice on the development of governance, technology and key deliverables, as well as the PROMs selection in direct interaction with the disease-specific work packages leaders.

The resources that PABs members will be able to provide, respectively the allocated budget for their involvement, are limited, hence their time and efforts are to be considered as a scarcity and these will be carefully and thoughtfully utilized.

### *1.6.6 Expectations towards PABs members*

Time commitment and workload from the 24 patients and patient representatives for the five (5) annual workshops are defined as follows:

#### Before a workshop

- One-hour meeting with EPF staff to update members of the PABs on recent developments in H2O.
- One-hour call with the WP leaders to have a better understanding of the work of each WP and the outcomes of the workshops.
- The Advisor is expected to actively contribute by providing the patient perspective about the workshop thematic. S/he may need to prepare a presentation or to contribute as defined by workshop organisers (work in small groups, break-out sessions, or others).
- Read documents in preparation for the workshop (previous meeting minutes, background bibliography, etc.).

#### a. During the workshop

One-day workshop. The Advisor is expected to actively contribute by providing the patient perspective about the thematic workshop. They may need to prepare a presentation or to contribute as defined by workshop organisers (work in small groups, break-out sessions, or others).

#### b. After the workshop:

- Members of the PABs should provide a feedback report based on EPF's template sent during the induction meeting. This report aims to capture the patients' views and perspectives on the workshop topic and her/his recommendations to the H2O consortium, if any.
- Provide the time sheets with the records of the amount of time spent in preparing, participating and reporting the workshop. EPF will provide you the timesheet template during the induction meeting.
- The Advisor would have the chance to contribute to the final report of the workshop and the time allocated for this task will be considered as an in-kind contribution to the project
- Additional tasks could be added to the previous list according to the workshops.

### *1.6.7 Members of PABs' expectations towards H2O partners and T1.5*

H2O WP1 leaders together with EPF and JDRF need to make sure the following pre-requisites are in place during the joint Induction Meeting (IM) of the three PABs:

- Make sure the Advisor is properly integrated and coordinated with the other Advisors to work as a team.

- Provide guidance and advice to Advisors, keeping them updated on the progress of the activity.
- Maintain oversight of the technical management of tasks and ensure that they are performed accurately.
- Validate the reimbursement claim forms, sent by the Advisors and proceeding to the booking of the travel and accommodation expenses (if any) incurred.
- EPF will contact the Advisor and provide relevant information and details of what the participation would entail (e.g., date, venue, length of meeting, topic address, etc.).
- EPF will support the Advisor throughout the process.

## 1.7. Remuneration

Members of the three PABs will be compensated for their time, efforts, and expertise within H2O project. These compensations have been internally agreed among WP1 partners, there is a dedicated budget envisioned and first payments should take place six (6) months after the PABs induction meeting. **EPF will be contracting all 24 members of the PABs with memorandum of understandings based on H2O D1.3, EPF internal code and procedures and Belgian Law.**

## 1.8. PABs Events 2021 - 2025

### Induction Meeting 2021

Following the completion and approval of the Bylaws, three PABs will be established, and an induction meeting will take place virtually, with EPF and JDRF in charge, and other H2O partners welcomed to participate, according to mutual agreement.

- Participants: all PABs members, WP1, WP3, WP4 and WP5 partners
- Tentative Description: One day meeting, presentation of the three boards, “who is who”

**Objective:** to introduce each other, discuss practicalities, agreed on timeline for 2021 and overall planning.

### Closing Event 2025

In 2025, three months before the official end of the project, there will be a closing meeting involving the following parties:

- All three PABs T1.5 partners
- H2O consortium members from across relevant WPs
- Other key stakeholders such as health care providers, health authorities, policy makers, researchers, regulatory and HTA agencies, Industry partners and patient community representatives.

**Objective:** to summarize the work done and set the scene for further collaboration in the very near future.

## 2. Conflict of Interest

The PABs members must take all measures to prevent any situation where the impartial and objective implementation of the action is compromised for reasons involving economic interest, political or national affinity, family or emotional ties or any other shared interest ('conflict of interests'). They must formally notify T1.5 and WP1 leaders without delay any situation constituting or likely to lead to a conflict of interests and immediately take all the necessary steps to rectify this situation. EPF, JDRF and WP1 leaders may verify that the measures taken are appropriate and may require additional measures to be taken by a specified deadline.

In case of doubt, members of the PABs should always contact T1.5 and WP1 leaders immediately.

## 3. Confidentiality

Members of the PABs should undertake that at any time, before or after the induction meeting, use or disclose or communicate to any person whatsoever any confidential information about H2O and/or EPF, JDRF is not allowed. Likewise, the Advisors should undertake to keep all deliverables, reports, minutes, project outcomes as **strictly confidential** and do not disseminate them to the outside world without prior approval of H2O, WP1 leaders and T1.5 co-leaders.

## 4. Timelines and workload

Main processes and procedures will be established in writing, entirely based on this deliverable. Separate timelines for various activities will be set in a form of plans: **1. Annual** and **2. Overall** plans and respective workloads will be agreed with members of the PABs, again according to the principles of this deliverable and previous experience of EPF with involving patients in IMI and EU-funded projects over the years. Both the annual and the overall plans will be aligned with WP1 partners' visions as well.

## 5. Bylaws Amendments

The present Bylaws may be subject to minor amendments if WP1 leaders and T1.5 co-leaders decide to do so. The H2O consortium members and the Innovative Medicines Initiative 2 Joint Undertaking shall be informed three months prior to the potential amendments of the Bylaws in written form.

## 6. Next Steps 2021

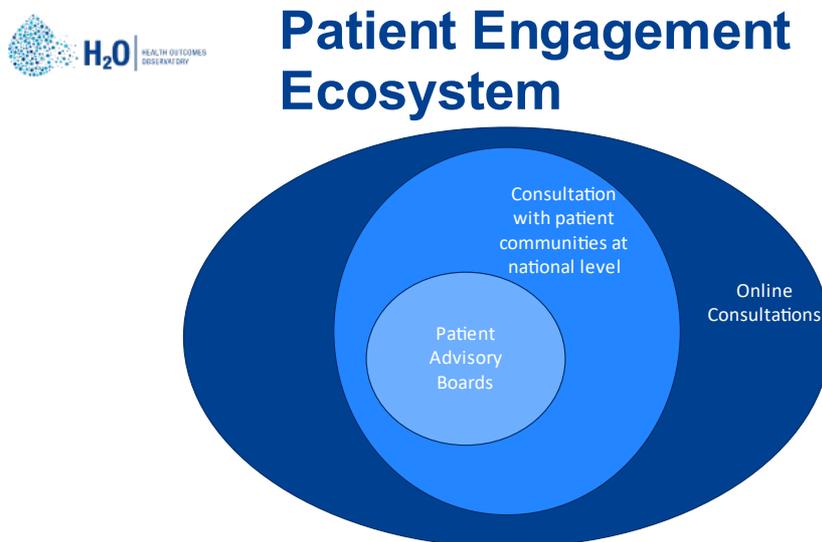
Following the approval of deliverable 1.3, EPF will be focusing on:

1. Formally inviting patients and patient representatives to join the three PABs (M6)
2. Selecting 24 patients and patient representatives after EPF and JDRF (together with disease specific WP leaders) agreed up the "ideal patient for the tasks" profiles and apply these criteria (M6) [See Annex I]
3. Setting up the three (3) PABs and holding/chairing the Induction Meeting (IM) (M7) [See Annex II and Annex III]

4. Designing the training and outreach materials for the PABs that will ensure alignment on rules of engagement, purpose and planning of the project, contribution expected by the consortium and to acquire notions of PROs and other topics relevant to the project (M10-M12).

## 7. Patient Involvement and Patient Engagement outside the PABs. General guidelines and recommendations

Patient involvement and patient engagement in H2O go beyond the activities related to the PABs and the overall idea has been presented and approved among partners. The graph below indicates the overall scheme for patient engagement in H2O for the next five years.



*Diagram 2*

As shown on diagram 2, patient engagement should go beyond the activities related to the PABs and should reach the patient communities on national level, mainly through the H2O country coordinators activities, but also with the support of WP1, EPF and JDRF networks and infrastructures in Europe. The country coordinators in Austria, Germany, Spain and the Netherlands should play a crucial role in this process. To facilitate the process and aid the country coordinators, EPF is suggesting the following recommendations and general principle:

- 1). Translation of materials into local language(s) would increase patient involvement, but also facilitate understanding of the project and boost interest among patients
- 2). Tasks/Activities should be presented and addressed in accessible/lay language
- 3). Patients need to be informed regularly on the progress of the tasks/activities where they are involved
- 4). Patients need to be involved from the very beginning of a task/activity, otherwise uptake is at risk
- 5). When involving patients in technical tasks/activities make sure everyone in the group “speaks the

same language” (build glossary of jargons, spend extra time explaining foundational/fundamental concepts)

6). There should be a balanced representation in terms of health literacy levels among patients, not only patient champions should be the ones involved

7). H2O Country coordinators should assign tasks/activities according to capability and capacity of the involved patients

8). Meaningful patient engagement should be fostered through established processes and mutually agreed objectives between the engaging parties.

## 8. Conclusion

This deliverable outlines how the three PABs can best contribute to achieving the ultimate goal of H2O project - creating, implementing and expanding a new paradigm that will systematically incorporate patients' perspectives in the healthcare of today. This document summarizes the steps that are needed in order to set up the three boards, select patients and undergo the operational side of the PABs. It also recommends general principles to engage patients and patient representatives outside the three Boards. This deliverable will be used when conducting the contractual agreements with the PABs members, defining the workload, and agreeing on objectives and timelines.

## ANNEXES

### ANNEX I. Profile Recommendations for members of PABs

Based on numerous EU-funded and IMI projects where EPF has been bringing the patients' perspective, the following recommendations are proposed when selecting and engaging with patients and patient representatives for the three disease-specific PABs:

- Representatives will be recruited after a thorough selection process based on motivation, expertise, experience and ability to share first-hand experiences in the disease areas.
- The composition of PABs will be balanced in terms of gender, age, socio-economic background, ethnicity.
- Patients and patient representatives must be free from “conflict of interests”
- Patients' profiles need to be representative for the patient communities in their totality, and not only the highly active, always vocal and empowered with high health literacy and having access to various resources patients to be invited onto the PABs.
- Members of the PABs should have an interest and understanding in PROs, PREMs, outcome sets, in digital solutions, e-health and m-health apps and trends.

## ANNEX II. Informal Invitation Template for patients to join the PABs

Dear *invitee name*

The European Patients' Forum (EPF) is reaching out to you on behalf of the Health Outcomes Observatory project, or H2O, to extend an invitation to join the project's Patient Advisory Board focusing on *insert condition*.

H2O is a public/ private partnership that aims to set up patient centric national pan-European observatories to strengthen the voice of patients in the individual relationship with their healthcare providers, but also in health systems more broadly.

The project will establish observatories in four countries, and focuses on diabetes, Inflammatory Bowel Disease, and cancer disease areas.

The project will have three patient advisory boards to make sure that patients are engaged from the start – consulting and advising on key project work from a patient perspective and ensuring that patients are meaningfully engaged throughout.

With your extensive experience/expertise in *XYZ*, we believe that your contribution to the *condition* patient advisory board would be an important part of the puzzle to help make the H2O project a success.

Does this sound like something you would be interested to participate in? If so, please do let us know and we can talk about the next steps and what to expect.

With warm regards,

*XYZ NAME, EPF*

## ANNEX III. Patient Organisations

National Coalition of Patient Organisations	European Disease-specific umbrella organizations
Netherlands' Patients Federation	IDF (Europe)
FEP - Spanish Patients' Forum	European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA)
NPO - National Patients' Organisation of Bulgaria	European Cancer Patient Coalition (ECPC)
Pancyprian Federation of Patients Associations and Friends (Cyprus)	
BAG Selbsthilfe (Germany)	
KUZ - Coalition of Associations in Healthcare (Croatia)	
Greek Patients Association	
EPIK - Estonian Chamber of Disabled People	
FPP - Federation of Polish Patients	
SUSTENTO - The Latvian Umbrella Body for Disability Organization	
VPP - Flemish Patients' Platform	
MHN - Malta Health Network	
AOPP - Association for the Protection of Patients' Rights (Slovak Republic)	
COPAC - Coalition of Patients' Organizations with Chronic Diseases (Romania)	