U-BIOPRED

innovative medicines initiative

A short guide to successful patient involvement in EU-funded research

Lessons learnt from the U-BIOPRED project

efpia
European Federation of Pharmaceutical Industries and Associations

Contents

Introduction

This is a short practical guide on how to involve patients across all stages of healthcare research. It is aimed at people writing applications for European Union (EU) healthcare research projects or who have had a proposal funded and are in the project development stage. You may find it useful to refer to throughout your project.

These top tips for successful patient involvement come from the experience of the Patient Input Platform (PIP) of the U-BIOPRED project (Unbiased BIOmarkers in PREDiction of respiratory disease outcomes), which is supported by the Innovative Medicines Initiative.

About the Innovative Medicines Initiative

The Innovative Medicines Initiative (IMI) is working to improve health by speeding up the development of, and patient access to, the next generation of medicines, particularly in areas where there is an unmet medical or social need. It does this by facilitating collaboration between the key players involved in healthcare research, including universities, pharmaceutical companies, other companies active in healthcare research, small and medium-sized enterprises (SMEs), patient organisations, and medicines regulators. This approach has proven highly successful, and IMI projects are delivering exciting results that are helping to advance the development of urgently-needed new treatments in diverse areas.

IMI is a partnership between the EU and the European pharmaceutical industry, represented by the European Federation of Pharmaceutical Industries and Associations (EFPIA). Through the IMI 2 programme, IMI has a budget of €3.3 billion for the period 2014–2024. Half of this comes from the EU's research and innovation programme, Horizon 2020. The other half comes from large companies, mostly from the pharmaceutical sector; these do not receive any EU funding, but contribute to the projects 'in kind', for example by donating their researchers' time or providing access to research facilities or resources.

Find out more: www.imi.europa.eu Twitter: @IMI_JU

About the U-BIOPRED project

The U-BIOPRED project is aimed to speed up the development of better treatments for patients with severe asthma. The U-BIOPRED consortium has created and validated innovative testing methods to classify patients into distinct severe asthma types. Data and samples have been collected, as well as clinical findings and patient-reported symptoms. This has been linked to results of preclinical models to facilitate future drug development.

The researchers have generated a 'handprint' – a combination of biological characteristics, which indicate what type of asthma a patient is suffering from. Patients have been divided into sub-groups, according to their handprint, to examine whether they react in a similar way to existing or experimental treatments for severe asthma so that the efficacy of candidate drugs is more predictable. Findings will help to speed up the development of new treatments leading towards a more personalised and targeted treatment of patients with severe asthma.

What is a "Patient Input Platform" in a research project?

The term "patient", in terms of patient involvement, can refer to people living with a condition, as well as caregivers and patient organisations. Patient involvement can optimise the ethics, relevance, accountability and transparency, communication, promotion and implementation of research outcomes. Patient involvement groups can be a Patient Input Platform (PIP), Patient Advisory Group (PAG) or Advisory Patient Forum (APF). All of these groups are composed of individual patients who bring their own experience to support a project. Throughout this guide the term PIP will be used.

The U-BIOPRED PIP was composed of 11 patients from 5 EU countries. PIP members were also active in the Ethics Board, Safety Monitoring Board and Scientific Advisory Board of the project. PIP was supported by the patient-focused project partners: Asthma UK, Longfonds (the Dutch Lung Foundation), the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), Lega Italiana Antifumo (LIAF) and the European Lung Foundation (ELF). U-BIOPRED PIP members were patients external to the consortium who were recruited by patient organisations but did not necessarily reflect their view. Costs in terms of travel, accommodation and subsistence were reimbursed to patients by the patient organisation consortium partners, in keeping with the IMI financial rules.

The project's PIP has drawn on its experience to publish an article in the journal, *Research Involvement and Engagement,* and produce recommendations for meaningful patient engagement in research. This booklet provides guidance and recommendations for patients' involvement in EU research projects starting from case studies from the U-BIOPRED project.

U-BIOPRED PIP members hope that by sharing their experiences of involvement, they can provide practical guidance to achieve successful and meaningful patient involvement to optimise your research outcomes.

"Patient involvement has been one of the successes to come out of U-BIOPRED.

The high level of commitment meant that the patient group became part of the core team in a number of WP.

This involvement is living on into our legacy period.

We would strongly advise other groups setting up research projects to consider the benefits of patient involvement, which go well beyond the usual 'user' perspective.

It is important to recognise the broader interest of patients in research, engagement of research in society and the additional perspectives from the professional and social backgrounds."

Neil Fitch, Innovation Project Manager, BioSci Consulting

Getting started

Involve patients as soon as possible

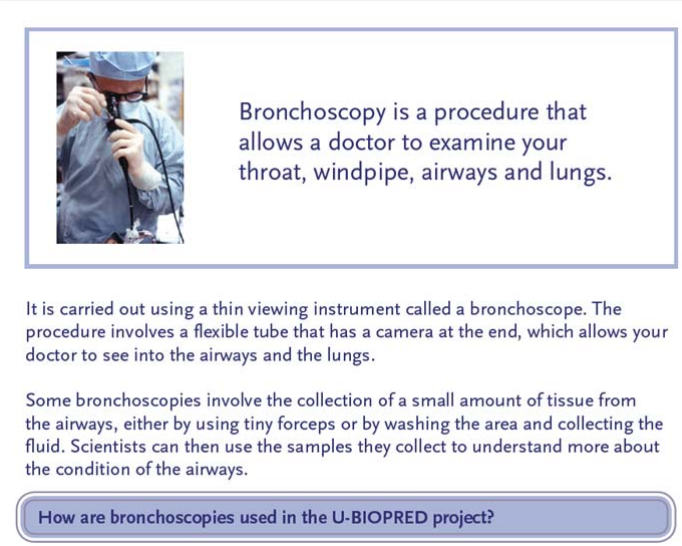
Patients can be involved as partners throughout the research cycle:

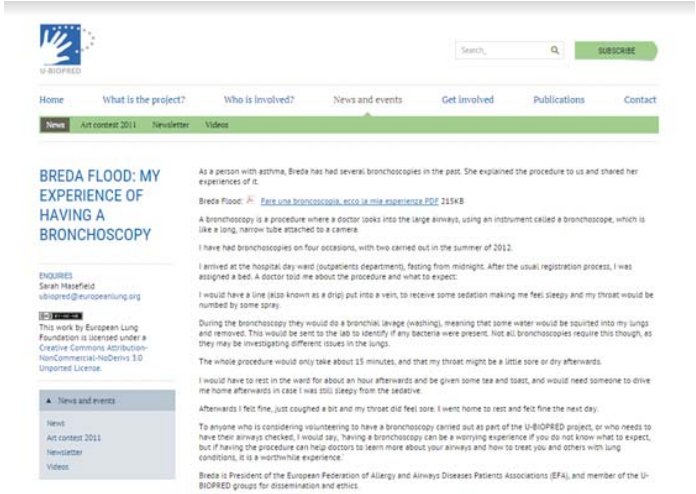
What	Why	The U-BIOPRED experience
Involve patient organisations as project partners	Patient organisations can help to plan, lead, guide and coordinate patient involvement during the project life-cycle.	Patient organisations were involved in U-BIOPRED applicant consortium as partners even before the proposed project submission. They contributed consistently in recruiting PIP members and in supporting them in all PIP activities.
Ensure patients identify and prioritise topics to be addressed by research from their perspective	To ensure that the project has relevance for patients and their outcomes are of interest to patients.	Longfonds and Asthma UK, two asthma patient organisations, joined the applicant consortium and provided advice and input even before the U-BIOPRED project proposal was submitted. *"It's crucial to involve patients from the outset. When the U-BIOPRED project was still in the planning stages, Asthma UK worked with the researchers and patient representatives to ensure the study focused on the issues which mattered to people affected by asthma.* *Patient involvement can help researchers approach their work from a new and valuable perspective, ensuring research impact is maximised for the benefit of patients."* ***Dr Erika Kennington, Head of Research, Asthma UK***

Include patients in the design and management of the project	To guarantee that the role of PIP is structured and that issues such as ethics and safety are covered in project implementation from the perspective of the patients who will be participating in the clinical trials.	PIP reviewed the project proposal and protocols, and defined the role of PIP in the project as well as within the Ethics and Safety Monitoring Boards. *"I think that, at the start of U-BIOPRED, few of us (myself included) knew what we could really expect from or ask of the patient representatives who took part in the project. It is now clear that their contribution made a real difference to the success of U-BIOPRED at many levels, not least on the Ethics and Safety board, their contribution to public awareness and dissemination of information. If we were to start U-BIOPRED again, I'd like to see a patient representative on the Management Board."* ***David D. Myles, Director Asthma Clinical Discovery at GlaxoSmithKline***
Train patients to represent themselves successfully	To ensure that all patients participating in the project possess the skills and knowledge needed to represent themselves and their interests successfully and interact with healthcare professionals, policymakers, researchers and journalists.	There are a number of e-learning or self-learning programmes introducing patients and carers to the essential skills and knowledge needed (see Further reading section). Patients can train themselves to learn new skills to understand better how decisions about healthcare are made and at the end of the training patients are normally ready to take part in activities such as input into guidelines, research projects, speaking at conferences, and explaining their concerns to policymakers and the media.
Train healthcare professionals to understand the importance of patients	To ensure healthcare professionals fully understand the importance of their relationship with patients and learn how to improve it and gain more from it.	Healthcare professionals can benefit greatly from patient input. Patient involvement motivates and emphasises the relevance of research and fosters empathy and the development of professional skills such as communication.

Ask patients to act as ambassadors for the project	The patients' voice is strong politically and helps to explain why certain aspects of a project are so important.	Patients have been speaking and presenting posters at conferences, such as CAREUM Congress (Basel 2014), ERS Congress (Barcelona 2013, Munich 2014, Amsterdam 2015), taking part in European Medicines Agency (EMA) activities, and discussing outcomes with other funding bodies and research projects in their early stages. *"As a patient representative, I specifically focused on the rights of patients and how they were protected. We made sure the rights and position of patients were tailor-made. And this was well-appreciated and accepted within U-BIOPRED. "* ***Martine Puhl, patient, member of the Ethics Board***

A PIP member on having a bronchoscopy, featured in a factsheet and on the project website to support recruitment for this optional data gathering examination.





Budget for effective patient involvement

Be realistic about the resources required for patient involvement throughout the project:

What	Why	The U-BIOPRED experience
Include costs for patient involvement in the project proposal budget	Costs of patient participation in annual meetings and other dissemination opportunities need to be covered. Costs include travel to events, meetings, accommodation and subsistence. Make due considerations on how you would support and engage patients – not everyone has the same availability or access to IT.	The European Medicines Agency (EMA) provides funding for patient involvement at a daily rate and cover costs of travel and accommodation. In the U-BIOPRED project, as the patients were external to the consortium, they were reimbursed for travel, accommodation and subsistence by the patient organisations consortium partners, in keeping with the IMI financial rules. It emerged that inadequate funds had been allocated for PIP travel but the partnership agreed to reallocate from other areas to ensure their participation could continue.
Include costs for a paid PIP coordinator	Calculate in person-months the work of a paid coordinator or Secretariat as part of the project.	Due to a change in the PIP leadership, several individuals and organisations became involved in the coordination of the PIP group in U-BIOPRED. It would have been better to identify and allocate one person/body from the outset that could commit to support PIP for the duration of the project.
Reimburse individual patients for their time where possible and give recognition for their work	Patients often take time off work and might have to find a replacement carer to participate in project activities. Patients should be motivated to stay involved and their commitment recognised.	The IMI and the EMA provide funding for patient involvement at a daily rate and cover costs of travel and accommodation. In U-BIOPRED, PIP's work was recognised through news and articles on their achievements published on the project website. Prizes and awards could also be created during the project, for example "outstanding volunteer of the year award".

Set up a Patient Input Platform

Bring together a group of patients to provide patient involvement:

What	Why	The U-BIOPRED experience
Aim for representativeness by recruiting widely	It is particularly important for representativeness in EU projects to involve as many countries and as many socio-economic groups and ethnicities as possible. Advertise the PIP role widely, through patient organisations, doctors' practices and on social media, to try and reach people from different backgrounds.	PIP would have liked the inclusion criteria for the group to also reflect the need for European representativeness as asthma affects people from all countries, all ages and all socio-economic backgrounds. It proved difficult to recruit individuals from many countries.
Set inclusion criteria	Inclusion criteria could refer to the condition/ issue that patients must have experienced or the range of countries and socio-economic groups to be covered.	In U-BIOPRED, PIP members had to have direct experience of severe or difficult-to-manage asthma as a patient, parent or partner; they also had to have good knowledge of English. The PIP drafted a Charter for the Patient Input Platform of U-BIOPRED (see Further reading section) enlisting the roles and activities performed by the PIP and thus facilitating patient recruitment.
Be clear about the project, patient involvement and patient's role	To ensure expectations are met and patients do not drop out of the project, provide a lay overview of the project and comprehensive information on its purpose and aims, as well as a PIP role description, suitable person profile, planned activities and expectations, including time and travel commitment.	A description of PIP, the Ethics Board and the Safety Monitoring Board was included on the U-BIOPRED website, but it was created for the PIP after it was formed. It would have been useful to have had the description beforehand to help the PIP to become established and know what to expect at the different stages of the project.

Set up an application procedure	Prepare an application process for PIP members, requesting details of their experience of the condition, previous involvement in research projects, availability and means for involvement.	PIP members were recruited by the national and European patient organisations who were partners in the project (Longfonds, Asthma UK and EFA) via an open call. Patient members were selected according to selection criteria and level of motivation. Ideally an initial 2-3 patients would have been involved in setting the inclusion criteria and in the reviewing of applications and appoint futher PIP members.
Maintain a consistent group of patients, but be ready to be flexible	Patients might not be able to attend all meetings or they might be forced to drop out because their condition might worsen, recruit enough members to input effectively.	A total of 11 patients were involved in U-BIOPRED Advisory Boards. Some had multiple roles: 9 in the PIP; 5 in the Ethics Board; 2 in the Safety Monitoring Board. These individuals came from 5 EU countries. Some were present at all meetings; some were unable to attend in person. These patients were external from the consortium although recruited by patient organisation partners of U-BIOPRED .
Be clear about the duration, amount and level of commitment required	Patients should aim to equally spread the work load amongst them so that it is not too onerous for any of the group members. There will always be some patients more active than others, which is not a problem unless they are influencing the patient representation in a way that is unrepresentative.	PIP members were invited to the Annual General Meeting each year. U-BIOPRED PIP members who could not attend any face-to-face events due to the severity of their condition were involved in all possible teleconferences and discussions by phone and by email. PIP members invested their time which varied greatly from the activity they were asked to perform as well as the project stage. In general, PIP members should expect to invest a minimum of 5 days per year, excluding event attendance. Depending on the role, PIP members were asked to input more in specific phases of the project.

Be clear about the language used in the project	The official language of most EU projects is English, thus patients involved must be fluent. Nonetheless, it is important to be willing to aid understanding in simple non-technical language and allow enough time for a response both verbally and in writing.	PIP members were proficient in English but for technical terms and complex concepts they relied on each other and the patient organisations for translation and comprehension.
Be clear on IT skills needed	Meeting in person is not always possible, which is why internet and computing tools are so important. They allow individuals living in different countries to work together, store information and communicate with no travel. But PIP needs to be representative of all socio-economic backgrounds, so efforts should be made to provide alternative ways of involving patients with low IT literacy or access.	PIP was given clear instructions on how to use smartsheets, teleconference services, project databases and social media channels. Guidance was provided on how to review project documents (e.g. MS WORD, track changes and add comments features).
Plan PIP involvement throughout the project	The project plan ensures patient involvement will be guaranteed, but also recognises the need to be responsive to changes as the research programme progresses.	PIP members were initially supposed to provide input in a defined number of WPs and tasks. PIP's level of involvement grew in the course of the project to include active participation in other WP discussions and outcomes, and in ambassadorial opportunities to promote the project.

During the project

Provide coordination and support for patients

Successful patient involvement relies on effective communication and facilitation:

What	Why	The U-BIOPRED experience
Give guidance on how to input	Advice on how to provide feedback on project tasks enables patients to participate appropriately in project activities.	PIP was informed how to participate in project meetings as well as whom to provide feedback for specific project activities.
Set up a secretariat	Within a complex project, the Secretariat helps patients to communicate their input into project activities, supporting and motivating them in their achievements. A project partner can act as Secretariat to coordinate patients' involvement in activities and logistics.	The PIP Secretariat was in charge of setting up teleconferences, dealing with expenses from the PIP group and helping with their travel arrangements, but also of coordinating the production of lay abstracts of research papers coming out of the project.
Pick a leader	Leaders are essential in creating cohesion within groups and in advocating patients' participation throughout the project. This should be a different person from the coordinator/Secretariat. Create a description of the leader and ask group members to appoint a leader internally.	A member of the PIP acted as the primary point of contact between other members of the PIP, the Secretariat and all project partners.
Give patients specific roles	Assign patients to different WPs or assign specific roles to patients in project boards, and provide training if needed. Confirm a term of office for each position.	Patient members of the Ethics and Safety Monitoring Boards and the Management Board received extra support and training, which turned out to be especially important to those PIP members without knowledge or skills in this area. This can provided by a project member with expertise in the area or via online or other courses on relevant topics (EPAP), such as medical ethics or medicines R&D.

Set timelines	To maintain project momentum and receive outcomes on time, the PIP should agree a turnaround time in keeping with the general project deadlines.	Members of the PIP agreed to be given 2 weeks to review documents such as information sheets and 1 week to give feedback on changes in protocol.
Create opportunities to meet in person	Face-to-face meetings are greatly beneficial for project progress and help consolidate patients' role and value within the project. When planning, check the venue is suitable, e.g. if people have mobility difficulties. Be aware that when medical conditions get worse, travelling might not be an option.	PIP met every six months. Patient members were also invited to annual project meetings.

U-BIOPRED Project Coordinator and the Chair of Patient Input Platform lead an educational session on how to involve patients in research projects at the ERS International Congress

"I believe the patients are professional if you consider their knowledge of their disease.

I believe that participation of patients is really needed to link health problems to research. It is important that patients are involved in research and help to disseminate research results back into society."

P. Sterk, U-BIOPRED Project Coordinator

Communicate regularly and clearly

Clear and regular communication allow patients to be well informed about the project and input most effectively:

What	Why	The U-BIOPRED experience
Make sure communication flows	Establish a protocol detailing how and who should keep patients informed on all project developments. This ensures nobody is left out and ongoing collaboration between the patients and project members is easier.	In U-BIOPRED, the coordinator gave monthly written and oral updates to the PIP. Before monthly teleconferences and annual meetings, PIP members received a short written update on the project's progress.
Tell patients about their impact	Information on changes brought about by patient input should be fed back to them, with an explanation on how actions or documents were changed.	Patients were informed on how research papers had been edited in response to their feedback, how recruitment was going after they had made suggestions, any protocol changes, ethics decisions informed by their perspective. *"As part of the biostatistics team you spend your life looking at spreadsheets of data and can easily forget where they came from. By working with a PIP, you realise this data comes from patients living with a condition that causes daily hardship. That this data requires them to take days off work to provide. That it's given in the hope that other coming after them will have better therapies. The hope that parents will not have to sit up all night watching their children struggling to breathe. That spreadsheet is no longer just a table of numbers but something much more important."* **Anthony Rowe, Director, Translational Informatics and External Innovation at Johnson & Johnson**

Engage regularly to maintain motivation	Ongoing engagement in a project requires regular contact and updates on project developments. This could be done through newsletters and involvement in activities by email.	Patients were involved in the project at least on a monthly or bi-monthly basis to ensure their ongoing engagement in the project.
Organise regular meetings	Facilitate regular meetings and calls – these may be more frequent at busy times in the project (beginning and end) and less frequent during specific tasks of the project (ie. data collection and analysis).	Consider carefully the tools selected to engage patients as these may vary according to the type of involvement and preference of users. Teleconferences and face-to-face meetings may be more appreciated than online forums and dedicated web platforms. A members-only forum was created for project partners but was poorly used by project partners and PIP grew frustrated with being the only participants. When the project website was updated, the forum was removed as email and teleconference proved more effective methods of inter-project engagement.
Encourage patients to take part in advocacy opportunities	Patients should showcase their involvement through external events and other research projects, and in reports on social media and websites. External interaction promotes awareness and interest in the project, and keeps members' motivation up.	Activities carried out by PIP to promote the project included: • a poster at the CAREUM Congress (Basel 2014) • participation in symposia and workshops at ERS Congress (Barcelona 2013, Munich 2014, Amsterdam 2015) • presenting in an ERS online course for healthcare professionals on patient involvement in research • EMA activities • helping develop an online learning module on patient involvement in EU projects

Support participant recruitment

Patients positively influence recruitment and reduce participant attrition. They know the condition that affects them and how it influences their decision to volunteer in clinical trials or projects:

What	Why	The U-BIOPRED experience
Ask patients' advice about the people involved in clinical trials	To ensure that patients taking part actively in the clinical trials are treated well, and that PIP are given the chance to advise on recruitment, ethics and dissemination strategies directly.	Patient testimonials supported recruitment for bronchoscopy by contributing directly to factsheets and in writing personal accounts on the project website. Patients also actively contributed to shape dissemination strategies.
Ask patients to support your recruitment process	Patients are able to optimise recruitment at all stages of the project by suggesting dissemination opportunities and channels. They should be consulted when the recruitment plan is put together, to help decide on the number of visits, duration, any optional tests.	PIP members had practical and professional experience in addition to their patient experience which impacted positively on the project. PIP members had skills in marketing, data protection, law and project management.
Ask patients to review information and documents	Patients can help to translate complicated documents into simple language, highlighting what key issues for patients might be: time needed for participation in a project, location of study centres and relevant contact details.	PIP reviewed informed consent forms for lay language and suggested the inclusion of details which were important to them, such as patient's privacy, possibility to file complaints, potential risks and measures to address them. PIP also produced patient information for patients entering or considering volunteering for the rhinovirus study in U-BIOPRED.

PIP produced a leaflet for patients entering or considering volunteering for the U-BIOPRED rhinovirus study.

Promote and disseminate the outcomes

Patients show the human side of scientific research. Patients involved in research know well how to adapt scientific communications for a non-scientific audience:

What	Why	The U-BIOPRED experience
Decide together	Project websites are powerful tools used for internal and external communication. Involving patients in designing and developing such tools makes the project more relevant to the public, policy makers and funding agencies as well as reaching the widest possible audience.	PIP has been instrumental in extending the reach of U-BIOPRED to other patients, public and public health/policy audiences, as well as to non-asthma specialist healthcare professionals, such as primary care doctors. When U-BIOPRED's website was revamped, PIP was consulted on which content to keep, update or remove, as well as on the style, layout and language.
Ask patients to do their part	Patients could produce regular project updates for interested people like other patients and the public outside the project.	News and reports written by patients were published and shared on the website, on the newsletters and on social media. Patients were very active on Twitter and LinkedIn and shared project and news stories with their followers. PIP also decided the content and co-wrote the U-BIOPRED newsletter, which was disseminated to project participants via the recruitment centres and project website. *"What stuck in my mind is the power of the hashtag on Twitter to reach a much wider audience. In January 2012 I set up my personal Twitter account. By the end of 2015 I had 3,850 followers. Tweeting #Ubiopred is a way of spreading what we are doing to an even wider audience."* **Val Hudson, PIP member**

End of the project

Promote the research findings outside the project

As the project comes to an end, patient involvement helps to give the real-world context to the findings and expands the project's visibility into public, patient and policy settings:

What	Why	The U-BIOPRED experience
Implement findings	To ensure that project results are tangible with a real-world application and communicated widely. Legacy activities should be promoted to continue the work of the project after EU funding has ended.	PIP was a strong supporter of exploring opportunities for continued funding after the EU funding ended, to ensure the continuation of U-BIOPRED's work so that real-world outcomes can be realised, i.e. raising awareness of the need to bring personalised medicine into clinical practice.
Evaluating impact	To ensure that patients can assess and provide their perspective on project outcomes. To ensure that the experience of the patients taking part as participants is also evaluated.	PIP introduced an exit questionnaire for study participants to receive feedback on their experience of the clinical trial, and to learn what improvements could be made in future studies. PIP has given valuable insight on how to maximise recruitment and attrition of participants; however it remains difficult to objectively measure the impact of PIP on these outcomes.
Motivate patients to complete what they have signed up for	Not all deliverables and products for dissemination are ready before the project funding ends, therefore patient involvement might be especially important after the project ends.	Many U-BIOPRED research papers will be published after the project's EU funding has ended. PIP are keen to ensure that lay abstracts of papers are produced, that teleconferences continue and the project website is maintained.

Always keep patients updated	It is important to have a plan for how to keep patients involved and updated when funding ends. Make arrangements to inform them on ongoing project outcomes.	Before project completion, PIP was asked to contribute to a final newsletter/update for clinical trial participants. PIP stressed the importance of receiving project results. As there is no funding at the end of the project for additional newsletters, updates were sent by email to those who subscribed to U-BIOPRED mailing list and published on the project website.

Provide opportunities to share knowledge and experiences

Patients sharing their knowledge and their own experience encourages others to get involved in healthcare projects:

What	Why	The U-BIOPRED experience
Update patients on other opportunities	Inform patients of other research projects they can be involved in and ask them whether they wish to become a mentor to others getting involved for the first time. Taking the lead and mentoring can steer the involvement of new patients in research and build their confidence.	Through project partners or other patient organisations, U-BIOPRED PIP members have been able to get involved in other EU-funded healthcare research projects (such as EARIP and MyAirCoach), as well as continuing to be involved with the patient organisation whom they originally came to U-BIOPRED through (Asthma UK, Longfonds, EFA).
Ask patients to set the agenda	Ask patients for their opinion on new research priorities, develop a policy paper and launch it in a European Parliament event by networking with project partners and patient organisations with lobbying experience.	Patients and patient organisations from different countries have been involved in research agenda setting either on a national level (Longfonds and Asthma UK), and at the European level (Asthma UK, EFA and ELF). It is useful to bring together the networks of patient groups and professionals involved in projects with the patient voice to reach the widest possible audiences with your research project and its results.

Further Reading

European Patient Ambassador Programme (EPAP) – self-training course, video and presentation slides: http://www.EPAPonline.eu

European Patients' Academy on Therapeutic Innovation (EUPATI) – webinar "Strengthening Patient Involvement in Health Technology Assessment" (video and presentation slides) http://www.patientsacademy.eu/index.php/en/32-news/events/539-webinar-strengthening-patient-involvement-in-health-technology-assessment-hta

European Patients' Academy on Therapeutic Innovation (EUPATI) - webinar "Interaction between Patients and other Stakeholders" (screencast and presentation slides) http://www.patientsacademy.eu/index.php/en/news/557-webinar-interaction-between-patients-and-other-stakeholders-in-the-medicines-development-process

International Alliance of Patients' Organisations (IAPO) reports on consensus framework for ethical collaboration between patient organisations, healthcare professionals and the pharmaceutical industry: https://www.iapo.org.uk/news/2015/jan/26/growing-support-shared-ethical-principles

EURORDIS Patients' Priorities and Needs for Rare Disease Research 2014 - 2020 position paper: http://www.eurordis.org/sites/default/files/publications/what_how%20_are_disease_research_0.pdf

Supple et al. on behalf of the U-BIOPRED PIP group (2015) From tokenism to meaningful engagement: best practices in patient involvement in an EU project. *Research Involvement and Engagement*, 1:12.

U-BIOPRED PIP group (2012) Charter for the Patient Input Platform of U-BIOPRED http://www.europeanlung.org/assets/microsites/ubiopred/files/charter-and-criteria-for-pip.pdf

Acknowledgements

The authors of the booklet are the U-BIOPRED PIP, who were supported to put this booklet together by the European Lung Foundation and the patient organisations involved as partners in the U-BIOPRED project: Asthma UK, Longfonds (the Dutch Lung Foundation), the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) and Lega Italiana Antifumo (LIAF). They would like to thank PIP's Chair David Supple and all of its members: A. Roberts, D. Supple, D. Hamerlijnck, J. Negus, J. Kamphuis, L. Sergison, L. Visintin, S. Onstein, M. Puhl, L. Buzermaniene, V. Hudson, L. Bond and P.A. Wecksell. In addition, the authors would also like to thank all the patients who have been instrumental in influencing, designing and undertaking actions envisaged by the project.

Last, but certainly not least, we are also most appreciative of the support and guidance that P. Sterk, P. de Boer, T. Teunissen and Biosci Consulting provided.

The U-BIOPRED project and research leading to these results have received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115010, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007- 2013) and EFPIA companies' in kind contribution.

U-BIOPRED consortium members at the Annual General Meeting

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