Workshop
Patient Engagement Strategy for Innovative Medicines

Active patient participation in research:
Case Study > U-BIOPRED

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Disclosures

- Independent patient representitive
- Chair of Patient input Platform U-BIOPRED.
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- Executive Board Member of European Association of System Medicine

Active patient participation in research.
Involving patients in U-BIOPRED

- A short guide to successful patient involvement in European Union funded healthcare research projects: lessons learnt from U-BIOPRED

- Now picked up by IMI into a funded booklet to support the research community

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

Lessons learnt from the U-BIOPRED project

What is U-BIOPRED?

U-BIOPRED

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U-BIOPRED (Unbiased BIOmarkers in PREDiction of respiratory disease outcomes) is a research project using information and samples from adults and children to learn more about different types of asthma to ensure better diagnosis and treatment for each person.

The U-BIOPRED consortium includes representatives of all stakeholder groups by involving 20 academic institutions, 11 biopharma industry partners (EFPIA), 6 patient organisations, 3 small to medium enterprises and 1 multinational industry, in 11 European countries.

PATIENT EXPERTS

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

- Different names are used for patient involvement groups, such as a patient input platform (PIP), patient advisory group (PAG), or advisory patient forum (APF). However, these are all groups composed of individual patients who bring their own experience to support a strong project.

- U-BIOPRED Patient Input Platform was composed of 11 patients from 5 countries. Patient Groups Asthma UK, Longfonds and EFA and the ELF were partners in the project and were involved in PIP Support, ethics, safety and dissemination.

PIP Lifetime : Working Together
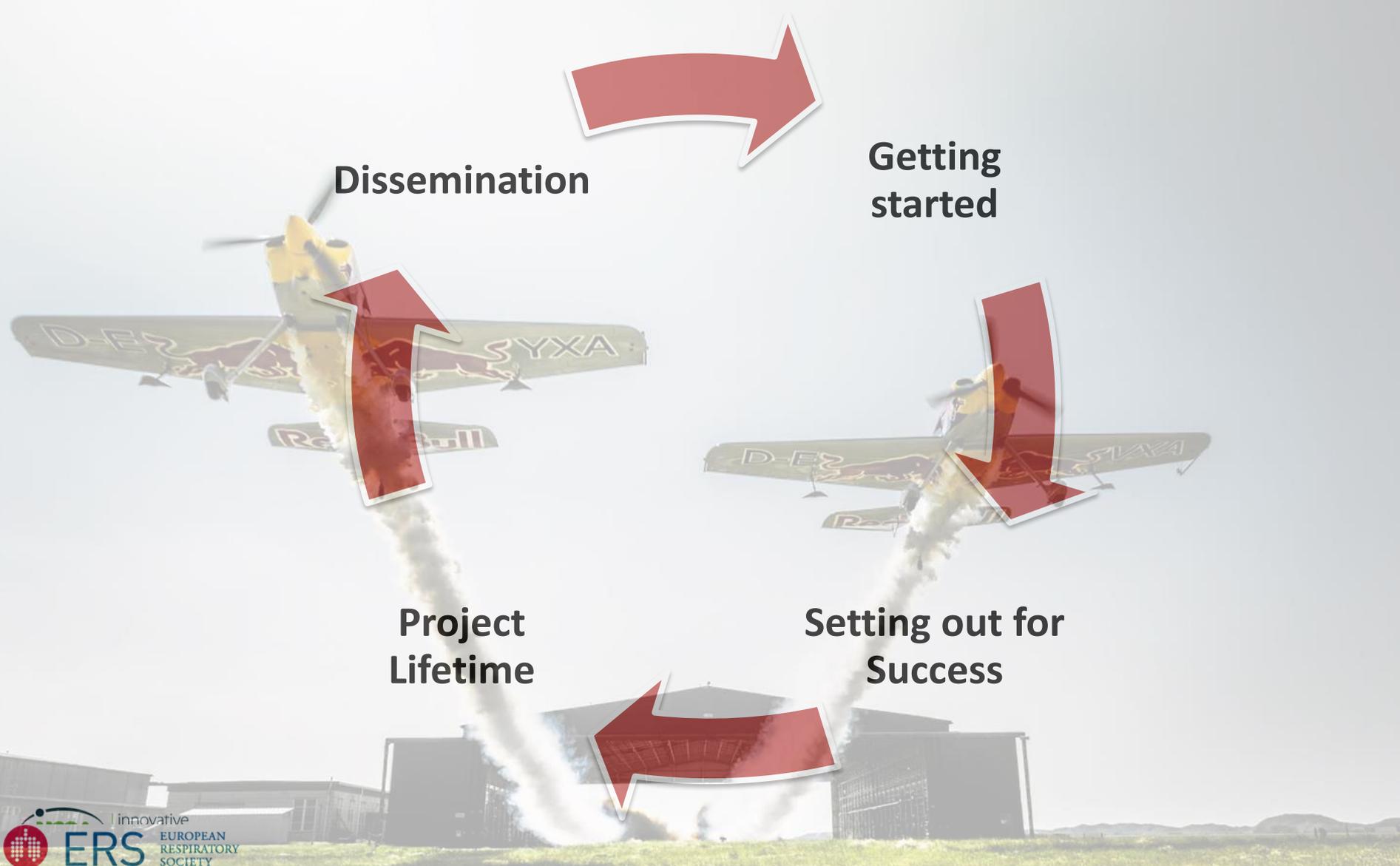
Getting started
Involve patients as soon as possible

Patients can be involved as partners throughout the research:

- Identifying and prioritising topics to be addressed by research from the patient perspective – *ensuring that the project has relevance for patients*
- Designing and managing the project
- Conducting
- Disseminating
- Implementing findings
- Acting as ambassadors for the project
- Evaluating impact

Making a successful PIP
Bring together a group of patients to provide patient involvement.

- Top tips for a successful group:

    1. Have a clear plan in place for how patients will be involved throughout the project, while being responsive to developments.

    2. Set patient involvement inclusion criteria (the condition/issue that they must have experience of, or from the range of countries and socio-economic groups that should be covered).

    3. Aim for representativeness by recruiting widely.

    4. Maintain a consistent group of patients, *but allow for those to come in and out where in case anyone becomes unwell and cannot contribute or has to leave.*

    5. Involve patient organisations as project partners as they can help to plan, lead, guide and coordinate patient involvement during the project life-cycle.

    6. Provide a lay overview of the project and role description, with clear and comprehensive information on the background to the project, purpose and aims.
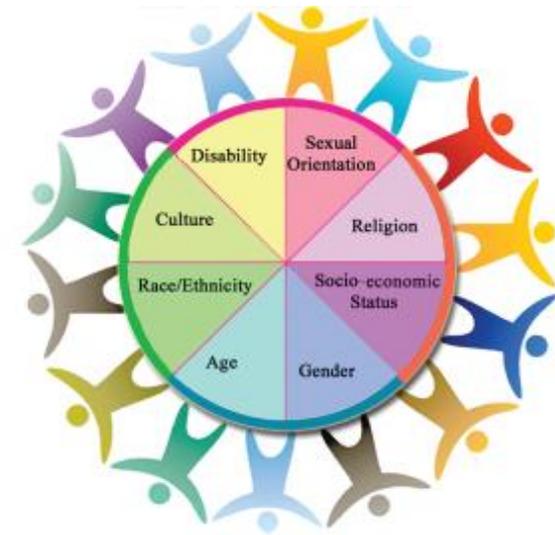
…a successful PIP

8. Be clear about the overall objective, suitable person profile, planned activities and expectations for involvement from the outset.

9. Be clear about the duration and level of commitment required. Enable patients to participate but also make it clear that they do not have to participate in every opportunity > *spread the work load amongst group members.*

10. Ask potential patient members to complete an application outlining their experience of the condition, (prior) experience in research projects, and why they want to get involved.

11. Establish patients availability and their means for involvement (e.g. access to computer/internet, proficiency in English) – involve patients in reviewing applications, interviewing and appointing the other members.

12. Be clear that the official language of most EU projects is English – but provide support through simple non-technical language with enough time for response.

During the project
Provide coordination and support for patients

1. Designate a project member/partner who can act as the PIP's secretariat (admin support) and coordinate their involvement in activities.

2. Appoint/elect a chair or leader of the patient group - *essential for cohesion and advocacy.*

3. Provide guidance on computing tools that will be used and in terms of content.

4. Include all patient members in annual project meetings and any other face-to-face meetings, to help consolidate the role and value of the group within the project. *Be aware that certain times of the year may make it harder for patients to participate in meetings due to ability to travel due to medical condition. Ensure that the venue is suitable for the patients.*

5. Assign patients to different project work packages and/or assign specific roles to patients in project boards. Confirm a term of office for the assigned roles with all patients.

6. Don't be afraid of setting deadlines.

Communication
Do communicate regularly and clearly

The PIP can input most effectively if they are well informed about the project, which can be achieved by:

1. Regular reporting mechanisms in place for all project developments to be communicated to the patients. There must be good communication between the PIP coordinator, patient group chair, project coordinator and work package leads .

2. Giving feedback to the patients when and how the project has been impacted by their input

3. As a rule, patients need to be involved on at least a monthly or bi-monthly basis to ensure their on-going engagement in the project.

PIP Coordinator

WP Leads

PIP Chair

Project Coordinator
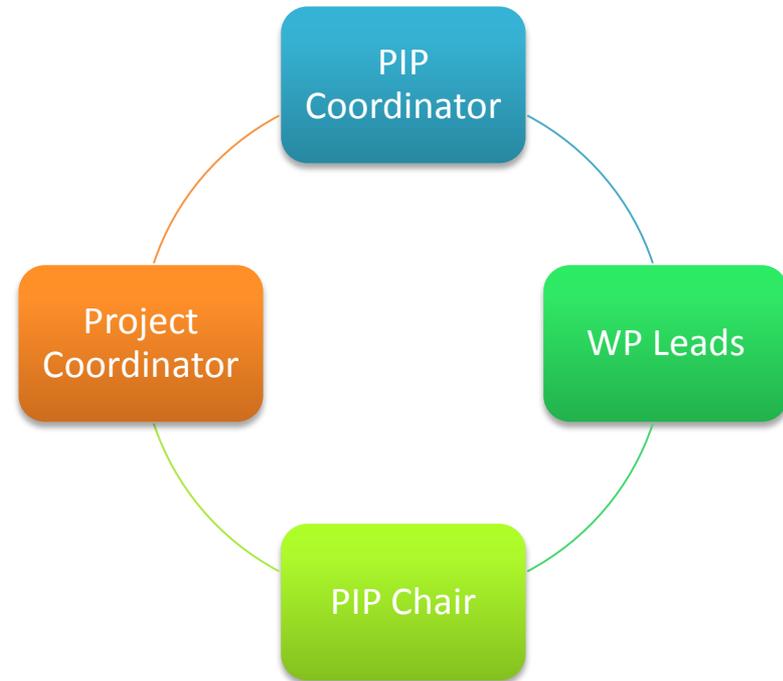
Communication
Do communicate regularly and clearly

5. Facilitate regular meetings and calls – this may be monthly at busy times in the project, but there may be less for them to input into during the data collection and analysis stages of the project. Keep them engaged!

6. Encourage/facilitate patients taking part in related external conferences and activities to showcase their involvement and the work of the project.

7. Short reports on project advocacy opportunities can be shared in project communications through social media channels and via the project website, helping maintain motivation and interest in the project.

8. Clearly state what response is required when you ask the patients to input.

9. Encourage communication between patients and project members, especially during annual meetings. Be a matchmaker!

Recruitment
Involve patients in recruitment strategies

Patients have real-world 'condition' understanding, so can aid recruitment and attrition strategies:

1. Consult with patients on your recruitment plan at the beginning when the plan is put together including on the number of visits, duration, optional tests etc., and throughout the project.

2. Patients can also advise/suggest dissemination opportunities to optimise recruitment.

3. Review information sheets to ensure that they are in lay language and cover the most important issues to patients.

4. Review informed consent forms for lay language and inclusion of details important to patients.

Recruitment

Attrition
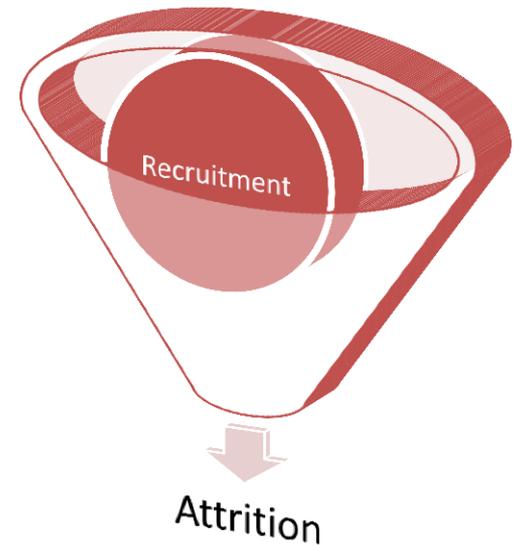
Dissemination
Do involve patients in dissemination

Patients involved in research have a clear role in helping adapt scientific communications for a non-scientific audience:

1. Helping produce regular project updates for interested people, usually patients and the public outside the project.

2. The PIP can be involved in designing the website, developing and maintaining content and social media channels, helping to reach the widest possible audience with the project.

3. PIP members can also get involved in translating material.

Dissemination
Promoting the research findings to those outside the field

Continuing to involve patients in dissemination activities as the project comes to an end:

1. Support patients in completing the tasks they signed up to during the course of the project lifespan

2. Review of information sheets that will be sent to the clinical trial participants to feedback on the developments within the project, so that they cover all relevant issues for patients; such as:

   – what has been achieved,

   – how will this translate into the clinical practice (and in different countries which have different healthcare delivery models).
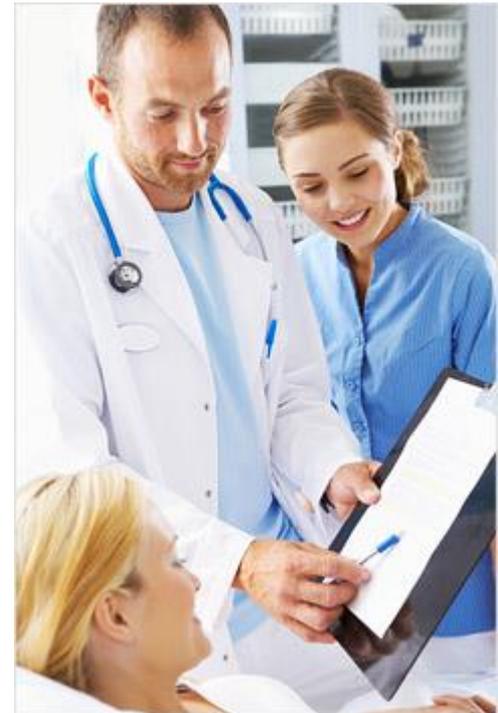
Dissemination / Knowledge Management
Opportunities for patients to share their knowledge and experiences

Encouraging and facilitating reflection on the project and the impact of patient:

1. Follow up with patient members of the project on whether they wish to become part of a mentor programme that can steer the involvement of new patients in research.

2. Inform patients of relevant other research projects they can be involved in.

3. Contribute to defining new research priorities and questions, work with project partners and patient organisations with lobbying experience to develop a policy paper and launch it with a European Parliament event.

ROLE of COLLABORATION IN REFLECTION

THE INDIVIDUAL

LEVELS OF INSIGHT

REFLECTION POINTS

THE COLLECTIVE
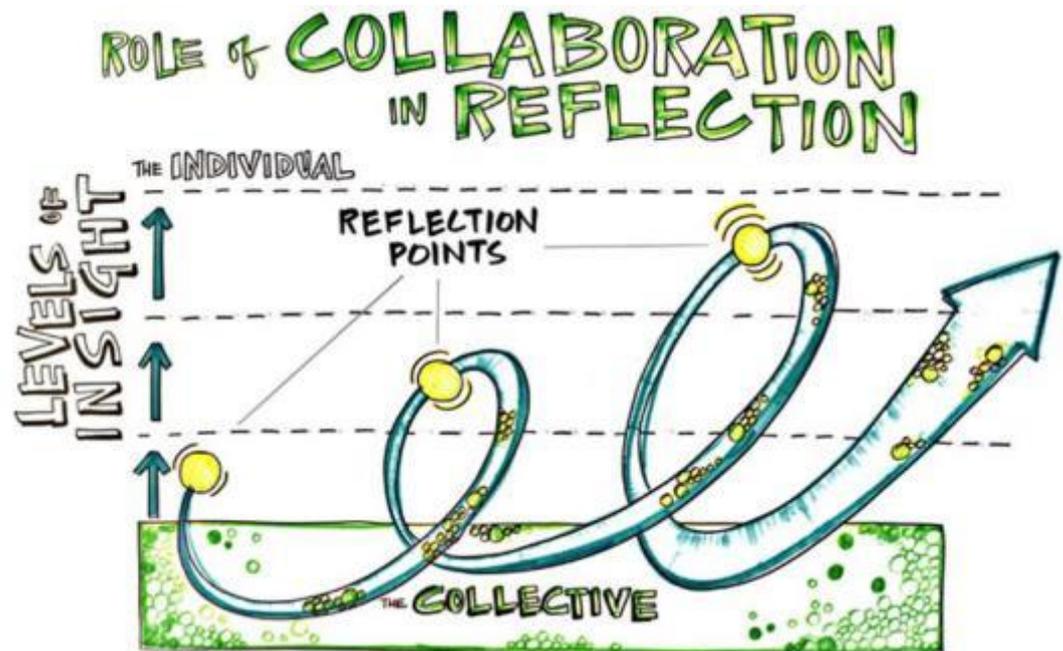
Did you remember the budget?

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

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Lessons learnt from the U-BIOPRED project

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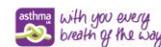
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