

Guidelines

Patient Involvement



IAPO recommends these guidelines are followed by international, regional, national and local organizations to involve patients and patients' organizations in *all* activities related to healthcare policy, systems and delivery, whether formal or informal.

You can use these guidelines as a project checklist:

- ✓ = Guideline has been met
- x = Guideline has not been met
- = Guideline not applicable

1. Identify issue and set out the objectives

- Identify the process, activity or issue which could impact on patients
- Determine the initial scope of the proposed activity; be realistic bearing in mind the planning and implementation phases
- Identify your objectives and consider the stakeholder groups to be involved
- Consider the benefits and challenges of patient involvement, for you and for the patients
- Aim to engage stakeholders in all phases of the activity from as early as possible (e.g. design, implementation, communication, evaluation)

2. Identify appropriate patient representatives

- Ask patients and patients' organizations to determine who the stakeholders are on their side and who could best represent them in your activity
- Use varied methods to identify and engage patient representatives (e.g. through patients' organizations, general and specialist media, publicity campaigns using websites and print materials)
- Try to be inclusive of underrepresented groups (e.g. the elderly, minority ethnic and religious groups, those with impaired mobility) and consider balance (e.g. age, gender, disease area) and the representativeness of the patients or patient representatives involved

3. Encourage participation and motivate

- Encourage participation by demonstrating the importance of the issue, providing supporting information and evidence
- Be transparent to build trust
- Be specific and avoid vague phrasing - outline expectations, roles and responsibilities
- Provide feedback to build loyalty and to encourage continued engagement

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4. Determine appropriate methods of involvement

- Invite patient representatives to input into planning and to suggest objectives and methods; discuss and agree these
- Seek out and evaluate existing methods to avoid duplication of effort
- Use more than one method of involvement (e.g. inclusion on committees and steering groups, focus groups¹, consultation exercises, advisory networks, patient forums, online tools)

5. Give support to enable involvement

- Ask patients and patient representatives to define patients' needs in the project and accommodate individuals' requirements as much as possible
- Consider the requirements of patients with impaired mobility and health (e.g. accessible venue, time to rest)
- Bear in mind individuals' limits and needs (e.g. mobility, time, money, language constraints)
- Understand and plan for non-attendance of patients due to ill health or relapse
- Be approachable and listen to individuals comments or concerns about their involvement
- Provide realistic time scales
- Provide reimbursement for all expenses incurred and offer a per diem for the time provided by patient representatives (be aware that some may be unable or unwilling to accept this)

6. Provide information, education and training

- Ask patient representatives what information and training they need to be engaged in the project
- Provide appropriate training as necessary to ensure a balance of knowledge among stakeholders
- Ensure all materials and information are presented in an accessible format and suitable for culture, age, gender and mental and physical ability, conforming to health literacy principles where relevant
- Consider website accessibility, remembering that not everyone has access to the internet

7. Monitor the involvement – ensure that it makes a difference

- Ensure that involvement is ongoing
- Ensure that patient representatives are equal participants
- Record results and, more importantly, act upon them to implement changes

¹ A focus group is a small group of stakeholders brought together to discuss an issue.

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8. Evaluate the project

- Review involvement mechanisms regularly, incorporating patient feedback to implement improvements
- Involve patients in helping you to develop new objectives and modify existing ones

9. Recognize involvement

- Thank all participants that have contributed to the project
- Publicly acknowledge participation (e.g. if input has contributed to final documents, acknowledge this)

Think holistically – beyond the individual project

10. Reassess internal frameworks

- Examine methods of policy development, implementation and evaluation, identifying potential barriers to effective patient involvement and ways to address them
- Make appropriate changes to improve internal frameworks

11. Educate staff

- Make sure everyone in the organization understands the value and importance of patient involvement
- Share best practice internally and externally
- Look out for conferences and opportunities to train staff about patient involvement

Related Publications and Selected References

IAPO Policy Statement: Patient Involvement www.patientsorganizations.org/involvement

IAPO Policy Statement and Guidelines: Health Literacy www.patientsorganizations.org/healthliteracy

Thompson AGH, (2003/2004). Moving beyond the rhetoric of citizen involvement: Strategies for enablement.

Eurohealth, 9(4): 5-8 (further references are available at www.patientsorganizations.org/involvement)

IAPO is a unique alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world.

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