Patient and Public Participation Tool

Imperial College Health Partners (ICHP) is a partnership organisation bringing together the academic and health science communities across North West London, and also the designated Academic Health Science Network for this area. We’re here to deliver demonstrable improvements in health and wealth for the people of North West London and beyond through collaboration and innovation. The involvement of patients and public in our work is crucial given they are the ultimate beneficiaries of everything that we do.

Our Patient and Public Participation Framework describes how we developed our approach to patient and public participation. This tool was developed as a result of the recommendations from the framework. It is intended to support those working in or with Imperial College Health Partners, to help guide how they should involve these groups.
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The involvement of service users and citizens in ICHP’s work is crucial given they are the ultimate beneficiaries of ICHP programmes. We wanted to explore how we can work in genuine partnership with people who use health services and live in North West London. To do this, we interviewed a range of internal and external stakeholders, and conducted desk research into best practice. The results from this research work can be viewed at ICHP Patient and Public Participation Framework.

As a result of this work, we agreed a set number of principles for how ICHP should conduct patient and public participation. These principles should be followed when using this tool to decide how to involve patients and the public in your work.

### Principles for involvement

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<td>Reward service users and carers for their contribution.</td>
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<td>Ensure there is clarity of purpose to the participation.</td>
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<td>Consider carefully how to communicate with service users and carers.</td>
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<td>Facilitate a service-user led process.</td>
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<td>Create a space for equal partnerships between professionals and the public.</td>
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Consider the programme goals.

Map the people who will be impacted by the programme, such as those living and working in North West London.

Consider the purpose of involving people. What will members of the public do? Will they be an ambassador, critical friend, co-worker, consultant or expert by experience?

What change can happen as a result of this engagement activity?

What resources do you have to do this?

Get early buy-in from those who need to take account of the results of the process.

Clarify the roles and responsibilities of the different participants, and what is expected of them all at different stages of the process.

Explain to participants exactly what will be done with their contribution and how the process will be managed.

Plan to feedback to participants how the findings will be used to achieve the project purpose.

Ensure that you and the patients and public are united in your motivations and expectations for the engagement.

What level of involvement do you want from patients and public? Some definitions are given on the next page.
Define purpose for your patient and public participation

Key issues to consider when defining your purpose

Devolving

Are you hoping to place decision-making in the hands of the community and individuals? For example, Personal Health Budgets or a community development approach.

Collaborating

Are you working in partnership with communities and patients in each aspect of the decision, including the development of alternatives and the identification of the preferred solution?

Involving

Are you hoping to work directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered? For example, partnership boards, reference groups and service users participating in policy groups.

Consulting

Will you obtain community and individual feedback on analysis, alternatives, and/or decisions? For example, surveys, citizens’ panels and focus groups.

Informing

Will you be providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities and solutions? For example, websites, newsletters and press releases.
A decision tool is available at the Involve Participation Compass, which guides users through some key questions about purpose:

http://participationcompass.org/welcome/index
The method of involvement will naturally emerge from the considerations of purpose. A decision tool is available at the Involve Participation Compass, which identifies the relevant method, depending on purpose:

http://participationcompass.org/welcome/index

Whatever the method, it is important to consider the following:

• How will you keep a record of the insights you will gather?
• What action do you plan to take with what you find out?
• How will you deal with sensitive issues?

• What are you doing to overcome particular barriers to taking part that some people may face?
• Are there any knowledge/skill gaps that need to be addressed to develop and deliver the technique?

The following list of participation methods has been taken directly from the Involve Participation Compass and selected because feedback from internal and external stakeholders has indicated that they may potentially be beneficial for ICHP programmes. For a full set of techniques, including useful supporting materials, visit:

http://participationcompass.org
1. Co-design/co-production

The term co-production refers to a way of working where service providers and users work together to reach a collective outcome. The approach is value-driven and built on the principle that those who are affected by a service are best placed to help design, participate in and implement it.

**Strengths**

- Taps into the insights and expertise of those who are at the receiving end of public services.
- Enables users/citizens and professionals/politicians to work together as equals and learn from each other.
- Builds skills, confidence and aspiration among participants.

**Weaknesses**

- Difficult to manage well when dealing with larger groups.
- Can appear exclusive and unrepresentative to those users/residents who are not invited to take part.
- Requires a considerable time commitment on the part of both professionals and participants.
2. Crowdsourcing

Crowdsourcing is the practice of obtaining services, ideas, functions, or contacts from a large and undefined network of people. This process can occur online and offline, but it tends to involve predominantly online communities.

**Strengths**

- A collaborative process, which can involve a large amount of people at a relatively meaningful level.
- Able to reach a large numbers of people across the world.
- Its open nature brings transparency throughout the process and result.

**Weaknesses**

- Value and impact of the work put in by the crowd can be wasted if the project takes a different direction.
- There may be more incentive for contributors to complete tasks quickly rather than thoroughly.
- Sometimes a lack of iteration between the crowd and the client.
3. Open Space

Open Space is a meeting framework that allows an unlimited number of participants to form their own discussions around a central theme. Open Space might be used at an early stage in a project, to understand and frame the relevant issues.

**Strengths**

- Accommodates large and diverse groups.
- Unleashes creativity.
- Encourages a participant driven approach.
- Extremely flexible process.
- Builds better working relationships and a sense of community.

**Weaknesses**

- Cannot be used to direct people to a specific outcome.
4. Future Search

A Future Search conference is a way for a community or organisation to create a shared vision for its future. It engages a large group of stakeholders who take part in a highly structured process. Everyone with a stake in the issue is in the room, which produces a rich mixture of information and ideas.

**Strengths**

- Proposals are more likely to be acted upon if all stakeholders feel committed to them.
- The event is designed to help participants understand and appreciate the agendas of others, which helps them to enlarge the common ground they share.
- It is hoped that if a shared vision is created it will inspire participants into the future.
- People are often energised by seeing that complex issues can be tackled when the whole system is present, when they can identify common ground with other people and develop a shared vision and agree concrete actions.

**Weaknesses**

- Requires a long term commitment from participants; hence recruiting and retaining participants can be difficult.
- Can appear exclusive to those who are not included.
- Involves only a small number of people and therefore does not provide statistically significant data.
- Participants can become less representative over time; advisory groups may need to be renewed regularly.
5. Citizen advisory groups

Citizen advisory groups involve 10-30 members of the public who sit as a committee to inform and advise decision making over an extended period of time. Advisory groups can create effective and on-going dialogue that allow issues and concerns to be explored in depth, and ideally addressed, while the participants are still involved.

**Strengths**

- Can provide an early warning of potential problems and be a useful sounding board to test plans and ideas.
- Regular meetings over extended periods of time give participants a chance to get to know each other, which can help discussions.
- Citizens can introduce a fresh perspective to discussions, encouraging innovation.
- Citizen involvement increases accountability in governance due to the more transparent process.

**Weaknesses**

- Requires a long term commitment from participants; hence recruiting and retaining participants can be difficult.
- Can appear exclusive to those who are not included.
- Involves only a small number of people and therefore does not provide statistically significant data.
- Participants can become less representative over time; advisory groups may need to be renewed regularly.
Focus groups are guided discussions of a small group of citizens. They are normally one-off sessions although several may be run simultaneously in different locations.

**Strengths**

- High level of participant interaction due to the small size of the group.
- Can lead to a greater understanding of how people think about issues.
- Members can be specially recruited to fit demographic profiles.
- Good for getting opinions from people who would not be prepared to give written answers.
- Provides understanding of how people think about issues.
- Allows the client to have a greater understanding of what may lie behind an opinion or how people approach an issue.

**Weaknesses**

- Heavily dependent on a skilled facilitator.
- Easily dominated by one or two strong opinions. Some participants may feel inhibited to speak.
- Responses are not quantitative and so cannot be used to gauge wider opinion.
7. Outreach and development work

Reaching out to community leaders who command trust and can support service users to engage.

In addition, advocacy is a key but under-developed component for supporting people’s participation. It is especially important for people who are disempowered and isolated and this is true of many of those excluded by existing arrangements for user involvement.

Suggestions for outreach work include:

- Reaching out directly to service users – checking out their views and what works best for them.
- Reaching out to their communities – for example local black and minority; ethnic communities, travellers’ communities, people in residential services.

“Service users emphasise the importance of reaching out to involve service users, especially those identified as ‘hard to reach’, rather than expecting them to come to you.”

From: Peter Beresford, Beyond the Usual Suspects: Towards inclusive User Involvement–Research Report. Practical advice available at:

www.shapingourlives.org.uk/ourpubs.html
NHS England guidance for participation in commissioning has adapted Armstein’s original (1960) involvement ladder:

http://www.england.nhs.uk/ourwork/patients
Decide how you want to recruit people

Key issues to consider

• Who do you want to involve and why?

• Do you need to engage with a service user representative of wider interest groups, or experts by experience?

• How important is it that the group is demographically representative?

• How many people do you need to take part?

• Are you paying service users? How will you manage reimbursement?

• What kind of recruitment process do you need? Will people need particular skills or experience?

• Have you considered equality issues?

• How will you encourage people who are seldom heard to take part?
Decide how you want to recruit people

Useful tools

For practical guidance on how to have an inclusive approach to recruitment see:

www.shapingourlives.org.uk/ourpubs.html
Consider how you will continue to communicate with patients and public

Key issues to consider

• Publicise the launch of the process to the right audience, using a range of media including the internet and networks as appropriate.

• Provide clear and accessible information about the purpose of the process and what is going to happen when*.

• Inform people if plans are changed or the schedule slips.

• Keep websites and other information sources up to date throughout and after the process.

• Feedback to participants after the process ends, including communicating to them the impact of the process.

* Information should be offered in a range of different formats and languages. For example, easy read, braille and/or audio versions, and translated versions for those whose first language is not English.
Consider how you will continue to communicate with patients and public

Useful tools

For case studies of successful participation and co-design programmes see:

http://participationcompass.org/welcome/index

For information on language see:

http://www.shapingourlives.org.uk/ourpubs.html
Evaluation tells us about the impact of what we do and the effect this has on the intended participants or services. When things have not worked, evaluation can help to answer questions about why not. Planning the review and evaluation process as early as possible is important to ensure that the learning is gathered from the work as it happens.

It helps to plan to feedback to participants how successful the engagement was in developing outputs and achieving outcomes. Examples of outputs include reports, leaflets, focus groups, workshop data and survey responses. Desired outcomes might be a change to a product, serving patient needs or leading to an overall improvement in patient experience.

**Consider how you will:**

- Agree and document objectives and purpose, including participants’ objectives.
- Judge whether the level of participation, methods, range of responses were appropriate.
- Monitor and assess costs.
- Assess whether the ways in which the responses from the process, such as recommendations, were dealt with in an appropriate and effective way.
Decide how you will evaluate the process and report on impact

Useful tools

- A decision tool to support planning and evaluating cost-effectiveness:
  http://webarchive.nationalarchives.gov.uk/20130805112926/
  http://healthandcare.dh.gov.uk/economic-case-for-ppi/

- A guide to evaluating co-production:
  http://coproductionnetwork.com/page/measurement-and-evaluation
Resources

- National Association of Patient Participation
- Involve Participation Compass
- The Engagement Cycle
- NHS England Participation Guidance
- INVOLVE - national advisory group that supports greater public involvement in NHS, public health and social care research
- Collaboration for Leadership in Applied Health Research and Care
- Guidance on Public Value
- Participation Smart Guides
- Peter Beresford, Beyond the Usual Suspects: Towards inclusive User Involvement – Research Report
- NICE Public Involvement Policy
- National Survivor User Network and National Involvement Partnership 4PI National Involvement Standards (NSUN 2013)
- The Co-production Network
- Local government - research and analysis. Neighbourhood Community Budget pilot programme
• Dos and don’t’s for involving citizens in the design and delivery of health and social care. Catherine Durose, Liz Richardson, Helen Dickinson, Iestyn Williams.
• Northwest London Whole Systems Integrated Care: Co-production Touchstone
• Involve: Nine principles of deliverable public engagement
• Involve: Not another consultation! Making community engagement informal and fun
• Our Pathways through Participation research
• Public-i
• The Democratic Society
• Tavistock Institute
• Mutual Gain
• Patient and Public Involvement Solutions
• Dialogue by Design (part of the OPM Group)
• The Public Involvement Impact Assessment Framework Guidance; Popay, J and Collins, M (editors) with the PiiAF Study Group.

• INVOLVE: The Gripp 2 Checklist
• What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation. Antione Boivin, Pascale Lehoux, Jako Burgers, Richard Grol
• National Survivor User Network and National Involvement Partnership 4PI National Involvement Standards (NSUN 2013)