



# Developing a Patient and Public Participation Framework – our approach

## About Imperial College Health Partners

Imperial College Health Partners is a partnership organisation bringing together NHS providers of healthcare services (hospitals, mental health and community services), clinical commissioning groups (GP led bodies responsible for buying healthcare services on behalf of their local populations) and leading universities across North West London.

Our vision is to deliver real improvements in health and prosperity for the people of North West London through:

- Enabling the discovery of best practice and innovation;
- Supporting the adoption and diffusion of best practice at pace and scale;
- Contributing to economic growth in North West London and the wider UK.

To find out more about us, visit our website at [www.imperialcollegehealthpartners.com](http://www.imperialcollegehealthpartners.com)

You can also find us at:

 @ldn\_ichp

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# Introduction

Imperial College Health Partners (ICHP) is a partnership organisation bringing together NHS providers of healthcare services (hospitals, mental health and community services), clinical commissioning groups (GP led bodies responsible for buying healthcare services on behalf of their local populations) and leading universities across North West London.

As the ultimate beneficiaries of our work, it is of paramount importance that patients and the public have an opportunity to be involved and engaged in our projects, and to work with us to scope and deliver improvements across North West London.

Unlike the majority of our 21 member organisations, we do not have direct access to service users or provide a direct service to the population of North West London. This, therefore, presents a challenge when trying to involve patients and public in our work because:

- They may not know who we are or why we exist;
- We may appear “removed” or distant from making changes on the frontline;
- We operate at system level rather than local hospital or GP practice level.

We therefore wanted to explore how we can work in genuine partnership with people who use health services and live in North West London. Our aim was to design a framework of patient and public participation, and co-design the delivery of which, will:

- Enable people who use health services and live in North West London to actively participate in and influence the design, development and implementation of ICHP initiatives that will impact on them;
- Build an understanding of, and capacity for, participation and co-design in the Partnership and across local networks;
- Demonstrate the impact of participation and co-design activities;
- Consider how ICHP can provide value to the people who participate in our work and support them to be actively involved.

We wanted to develop a guide that project teams and stakeholders could use to support them in involving and engaging patients and the public, in an effective, evidence-based way.

In order to gain a clear understanding of the context, challenges and expectations for patient and public participation and co-design for ICHP, we commissioned an independent consultant to conduct in-depth interviews with a range of internal and external stakeholders.

Based on an analysis of these discussions and desk research into the latest thinking in participation, five key recommendations were made. Practical tools have now been developed to support the implementation of these recommendations, including:

- A set of agreed principles for participation and co-design (contained within this report);
- An online, interactive tool, designed to support the user through decisions about patient and public participation.

This report has been reviewed by the internal and external stakeholders who took part in the interviews and their feedback has been incorporated. We would like to thank everyone who has taken part.

## Terms used in this report

For the purposes of this report, the following terms have been used to ensure a consistency of understanding, as follows:

### Service users, carers and their families

We have used the term ‘patient’ and the title of the report and tool is ‘patient and public participation’, but are conscious that the term ‘patient’ is used solely in a health setting and the work of ICHP spans mental and physical health and social care. In a number of instances we use the term service users, carers and their families.

### Participation and co-design

These terms have been used as shorthand for all activities in the ‘ladder of engagement and participation’ (**Appendix 1**), from information and consultation through to shared design and delivery (co-production).

### Excluded and seldom-heard groups

These terms have been used to include people who might face equality or other barriers (on the basis of gender, ethnicity, culture, belief, sexuality, age, disability and class) or may be excluded in some way (homeless, living in residential services, in prison, travellers), or those who face communication issues (deaf people, blind people, people for whom English is not their first language).

### Public, citizen and community engagement

These terms have been used to describe activities that seek to enable larger groups of people to understand and influence decisions.

## Emerging themes from interviews and desktop research

A number of key challenges and opportunities for ICHP were identified in the evidence gathering and interview process. (See **Appendix 2** and **3** for the list of interviewees and interview questions.) These are set out in this section.

### 1. Embedding citizen voice in the work of ICHP

*“Patients keep us focused on what we are trying to achieve. They remind you that you are there to improve the quality of care for people.”*

Lis Paice, Chair of the North West London Integrated Care Programme

*“Start with governance – tax payers represent your consumer base, mesh their participation into the way of thinking, doing and leading. All my experience indicates that the root cause of failure can be tracked back to lack of leadership and poor governance.”*

Simon Denegri, Chair of INVOLVE

Unlike private enterprise, organisations providing public services are directly accountable<sup>i</sup> to citizens and their democratic representatives. ICHP is largely a publically funded organisation and, as such, needs to demonstrate good governance, accountability and public value. ICHP want to work effectively in partnership with people working in health and social care in North West London and the end users of care – service users and carers – and to reflect the service user, carer and citizen voice as part of its decision making<sup>ii</sup>; <sup>iii</sup>. There is an opportunity for ICHP to explore the membership and role of service users and carers and their representatives in key groups/committees within the organisation.

### 2. Articulating the ICHP mission to stimulate people in North West London to support the organisation and its objectives

*“What problem are AHSNs trying to solve? What would success look like and is that shared by the partners and the wider public?”*

Rachel Matthews, Patient Engagement Lead for Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for North West London

For ICHP to achieve its aims, far reaching and large-scale behaviour change across health and social care services will be needed. In order to achieve this, ICHP will need to engage people on both a rational and emotional level. It will not be enough to share clinical or operational evidence. In order to stimulate this level of change, people will need to understand, and buy into, the “why” of ICHP – the purpose and the cause.

ICHP is developing programmes that span health, social care, local government, academia and industry and, as such, are uniquely placed to get closer to people, understand their needs and work collaboratively to discover and encourage innovation and adoption and diffusion of best practice.

There is a thirst for a better understanding - both in local organisations and community groups and service users and carers for why ICHP exists, what it is there to do and how it will work and how it complements/ adds value to other organisations in North West London and established departments and institutes in universities.

ICHP has a desire to be known as an organisation that takes participation and co-design seriously, that challenges people to do things differently and identifies new ways of working with people.

There is an opportunity for ICHP to work with people who live and work in North West London to communicate and connect with the “why” of ICHP and its programmes, the story of the potential impact on people’s lives of ICHP programmes and the local relationships that will be needed to make ICHP a success.

### 3. Co-designing programmes with partners and people who live and work in North West London

There are a number of benefits to be had from increased co-design in the work of ICHP that directly support its **core aims** of discovering best practice, encouraging adoption of this practice and supporting economic growth.

*“We find that, with our teams, taking time to really understand the problem first and then move towards a shared aim can help build a collective purpose. This needs to be revisited frequently to maintain engagement.”*

Rachel Matthews, Patient Engagement lead for Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for North West London

Effective participation activity will help ICHP to realise its **core values**: to focus on the needs of patients, build a culture of partnership and collaboration and work inclusively and with equality.

To achieve this there will need to be an organisation-wide commitment to engaging across the whole system - the ICHP partners/members as well as the diverse groups of people who live and work in North West London - in all aspects of ICHP's work. This participation and co-design activity would pave the way for the external challenge, innovation, and creative working that will be needed for programmes to be a success.

There is learning from existing ICHP programme co-design activities that can be shared and built on - in particular the co-design of the psychosis pathway, which enabled extensive ideas generation with a group of service users and carers - and an opportunity to share learning from this activity.

There is an opportunity and enthusiasm for co-design and participation methodology to be the starting point for all programmes. This would mean that, if patients are equal partners, they would be part of integrated co-design, not a separate activity.

This will require a shared vision, a need to operationalise and embed participation and co-design as a core competency within ICHP and an acknowledgement that participation and co-design will require resource, support and the space and time to build relationships that are sustainable.

What is clear from those interviewed is that co-design and patient and public participation is a complex endeavour and requires balancing differing views from within patient and citizen communities together with research and other evidence. Alongside the support that is required for service users to get involved, health and social care staff also need support.

### 4. Working together

There are a number of people, organisations, and groups setting out to engage people who live and work in North West London and a number of systems and well-established networks already in place. However, this activity is currently fragmented, partly due to the widespread changes in health and social care. In addition, there is a danger of “consultation fatigue” and a perception that nothing really changes.

The interviews exposed a clearly expressed need and desire to work together to share information and plans and, where possible, join up endeavours. However, it was acknowledged by many that partnership working will be challenging as each organisation and group has its own remit and resources for participation.

*“An extraordinary amount of money is being spent on patient and public involvement activity, every organisation is doing it, but, it's un-coordinated. There are major opportunities for partnership working.”*

Professor Jonathan Weber, Director of Research, Imperial College, London

*“We need to move towards an integrated way of working, identify some projects to work on together and trust each other.”*

Trevor Begg, Lay member of Hillingdon Clinical Commissioning Group (CCG)

There is an opportunity for ICHP to support activities that bring people together across North West London to develop a shared vision for how to work together, showcase effective practice, identify innovations and to ensure a strategic approach for the area.

*“It’s really important to work together.”*

Markella Boudioni, Patient and Public Involvement Manager, Patient Experience Research Centre (PERC) & NIHR Imperial Biomedical Research Centre (BRC)

## 5. Demonstrating impact – both in ICHP programmes and through co-design and participation activity

The majority of people interviewed raised the impact of co-design and participation as a key challenge and one shared by all who work in this field. Whilst we instinctively know that participation and co-design make a difference, the impact is hard to track. There are programmes underway in the North West London Collaboration for Leadership in Applied Health Research and Care<sup>iv</sup> (CLAHRC) to determine how best to measure the impact of participation and co-design. In addition, the National Institute for Health Research (NIHR) will shortly publish ‘Breaking Boundaries – Thinking differently about public involvement in research’ the findings of its Strategic Review of Public Involvement. There is an opportunity for ICHP to learn from and implement, where appropriate, the findings of all of this important work.

ICHP recognises the need to demonstrate how it has been embracing co-design and participation activity to enable it to achieve its aims for citizens of North West London. It will be important to collect qualitative as well as quantitative data on the impact of participation and co-design, to plan impact evaluation at the start of every venture and to communicate the difference that participants have made to the results<sup>v</sup>.

*“The AHSN is small and nimble and can work to join things up.”*

Jeremy Taylor, Chair, National Voices

## Recommendations

The desktop evidence review, coupled with insights gained from interviews, led to a series of recommendations across the five themes for ICHP to take forward to develop its work in patient and public participation. As a result of the recommendations we have now developed an interactive tool for patients and public participation ([view the tool here](#)) and will be considering how best to take the other recommendations forward.

### 1. Embedding public/citizen voice in the work of ICHP

Unlike private enterprise, organisations providing public services are directly accountable<sup>vi</sup> to citizens and their democratic representatives. ICHP is largely a publically funded organisation and, as such, needs to demonstrate good governance, accountability and public value. There is an opportunity for ICHP to explore the membership and role of service users and carers and their representatives in key groups/committees within the organisation.

#### Recommendations:

- 1.1 Membership of ICHP Expert Advisory Board to consider how to include citizen/public representatives to bring participation expertise and challenge, thought leadership and networks. Based on the terms of reference for the group, the recommendation would be to invite a representative of a national citizen voice organisation.
- 1.2 ICHP to embed participation in governance arrangements and apply the Standards of Good Governance in Public Services<sup>vii</sup>.

### 2. Articulating the ICHP mission to stimulate people in North West London to support the organisation and its objectives

For ICHP to achieve its aims, far reaching and large-scale behaviour change will be needed. There is an opportunity for ICHP to work with people who live and work in North West London to communicate the potential impact on people’s lives of ICHP programmes and the local engagement that will be needed to make ICHP a success.

#### Recommendations:

- 2.1 All programmes to actively consider co-design opportunities and report annually on both co-design and participation activity and outcomes, as part of core communications and stakeholder engagement and annual reporting.

### 3. Co-designing programmes with partners and people who live and work in North West London

There are a number of benefits to be had from increased co-design in the work of ICHP that directly support its **core aims** of discovering best practice, encouraging adoption of this practice and supporting economic growth. Effective participation activity will help ICHP to realise its **core values**: to focus on the needs of patients, build a culture of partnership and collaboration and work inclusively and with equality. There is an opportunity and enthusiasm for co-design and participation methodology to be the starting point for all programmes. This will require a shift in established ways of working.

It is essential that those involved in the participation represent the population groups that the changes will have the greatest impact on. ICHP serves a diverse population group and special efforts must be made to encourage the participation of sometimes excluded and seldom-heard groups.

#### Recommendations:

- 3.1** ICHP to ensure space for challenge to existing thinking and action, and allow additional time in programme plans to enable programme teams to co-design with people who work in the system as well as patients and carers.
- 3.2** Ensure there is identified budget for participation and co-design activity within programmes for activities such as:
  - External support when required (eg: external co-design expertise, peer-to-peer engagement or recruitment activities);
  - Support to participants, including payment where appropriate and expenses;
  - Communication activities, including web based engagement such as crowd-sourcing;
  - Participation evaluation costs;
  - Participation event costs.
- 3.3** Provide appropriate development opportunities for staff, service users and carers, in partnership with others working in this space, to avoid duplication.
- 3.4** All at ICHP to make a special effort to encourage the participation of excluded and seldom-heard groups.
- 3.5** Develop a policy around payment for patients and citizens who get involved in our work. This will explore the potential to offer sessional payments, providing information about expenses as well as support with travel arrangements.

### 4. Working together

There are a number of people, organisations, and groups, setting out to engage people who live and work in North West London and a number of systems and well-established networks already in place. This activity is currently fragmented, which presents an opportunity for ICHP to support activities that bring people together to ensure a strategic approach for North West London.

#### Recommendations:

- 4.1** ICHP to explore with its members how to create a shared vision for how to work together across North West London. This could be developed via an event, complimented by on-line activity such as crowdsourcing, to showcase effective practice and innovation.
- 4.2** ICHP to work with key agencies to share principles and co-design and participation opportunities.
- 4.3** ICHP to consider creating and supporting a network/form and a shared web space, if appropriate, for such a group.

### 5. Demonstrating impact – both in ICHP programmes and through co-design and participation activity

ICHP recognises the need to demonstrate how it has been embracing co-design and participation activity to enable it to achieve its aims for citizens of North West London. This is a key challenge shared by all who work in this field.

#### Recommendations:

- 5.1** ICHP to learn from and feed into others on evaluating impact of patient and public involvement and engagement.
- 5.2** ICHP programmes to evaluate and report on all co-design and participation activity annually.

## Principles for participation and co-design

Drawing on insights from our stakeholder interviews and desktop research, we have developed a set of principles to guide our participation and co-design work.

### Background research

A recent randomised trial process evaluation, conducted in Canada, describes “the key ingredients likely to affect public members’ ability to deliberate productively with professionals and influence collective health care choices”. The findings indicated that “**legitimacy, credibility, and power** explain the variations in the public members’ influence<sup>viii</sup>”.

Their credibility was supported by their **personal experience** as patients and caregivers, and the provision of **structured preparation**. **Legitimacy** was fostered by the recruitment of a **balanced group** of participants and by the public members’ opportunities to draw from one another’s experience. The **combination** of small-group deliberations, wider public consultation, and a moderation style focused on **effective group process** helped level out the power differences between professionals and the public. The engagement of key stakeholders in the **intervention design** and implementation helped build policy support for public involvement.”

### Key themes from interviews

Interviewees highlighted the following factors as being crucial principles for patient and public participation:

#### Recruitment of people with personal experience and structured preparation:

- Identify which communities will be most affected by the programme. Those with most at stake must be represented the most;
- Be inclusive – reach out;
- Set expectations for the participants;
- People have the potential to reach out to other groups, pass information on, and get information back – a two-way flow is needed.

#### Recruitment of a balanced group:

- Spell out the purpose of co-design and participation;
- Be realistic about the difference that participation insights will make to the programme design and delivery.

### A combination of participation activities and group focused moderation:

- Value people equally;
- Listen and be open;
- Be aware that those who are involved can gain directly through gaining increased confidence, health literacy, social contact, news skills and employability.

### Engagement of people in the intervention design:

- Do not be afraid to fail and learn;
- Involve people from the start of the programme;
- Ask “What do they want to get out of it?”

An overriding message from the interviews was that it is important to make it as easy as possible for people to get involved and to “acknowledge the power differentials that exist between professionals and service users and commit to minimise them where possible.”<sup>ix</sup> Using these key themes, a set of principles was created to underpin ICHP’s participation and co-design work. It is clear from the desk research and interviews that a number of principles and standards for participation and co-design have been developed nationally and locally<sup>x</sup>. What follows is a summary of the principles that were recommended and commentary on why they are important for ICHP.

### Agreed ICHP principles for participation and co-design

#### 1. We will approach participation and co-design from the perspective of service users and carers

*“Treat people as equals.”*

Paula Murphy, Director of Healthwatch Central West London

People who are willing to make a contribution to the work of ICHP are a vital resource and their time and commitment needs to be valued.

*“Involving people in public health requires an infrastructure that is flexible, supportive and actively addresses barriers to engagement.”<sup>xi</sup>*

Engaging the Public in Delivering Health Improvement – Research Briefing for Practice, Leeds Metropolitan University

We will endeavour to:

- Ensure that participation and co-design activities are a positive experience;
- Consider how to make the experience interesting, fulfilling, empowering and, where relevant, fun for those involved;
- Identify ways for the experience to increase everyone’s understanding of the challenges that are being tackled and the role of citizens and service users in helping them to be overcome;
- Ensure that our approach to participation is flexible, well designed and consistent;
- Give careful consideration to environmental and cultural factors, venue, location, food and the whole experience of participation;
- Support people in their roles;
- Where relevant and possible, offer a range of opportunities for people to develop their skills and knowledge.

## 2. We will reward service users and carers for their contribution

People should be rewarded for their contribution wherever possible. ICHP acknowledges that this is a complex area, but we will be creative in our approach to valuing people’s time.

Our approach will involve:

- Developing a policy around payment;
- Exploring the potential to offer sessional payments;
- Providing information about expenses and booking travel in advance wherever possible;
- Seeking feedback from participants on what they hope to gain from the process and what development/other opportunities would be appropriate.

## 3. We will ensure there is clarity of purpose

*“Be clear about why you are doing it, aims and purposes, and what the people involved will get out of it.”*

Clive Mitchell, Programme Manager, Involve

Defining purpose will help us to share our commitment to change in response to the views of service users and carers. We will think carefully about the decisions that lie ahead and the insights we will need to inform them.

We will endeavour to:

- Seek to understand how people will make a difference to our work;
- Clearly state why we are involving people in our work;
- Match our technique to this purpose;
- Use an appropriate and transparent participant recruitment process;
- Determine how impact will be evaluated from the outset.

## 4. We will create a space for equal partnerships between professionals and the public

*“We need an approach based on empowerment.”*

Josephine Ocloo, Patient Safety Champion Lead for ICHP

“Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families, and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change.”<sup>xii</sup>

There are a number of ways to design an approach based on empowerment. Evidence shows that payment, reimbursement of expenses, training, good communication and access to knowledge and insight are all key ways of making the experience worthwhile for service user and carer participants.

### 5. We will carefully consider how we communicate

*“What actually happens? We need to make the connection back, so that people involved know the impact of their involvement.”*

Simon Roberts, Founding Partner at Stripe Partners

*People need to see the impact, feel part of something useful.”*

Alison Baker, Lay member, NHS Hounslow Clinical Commissioning Group (CCG)

We will endeavour to pay special attention to the following:

- Offering to print documentation and post to participants in advance of events;
- Being careful to communicate in good time;
- Avoiding long emails and long reports, especially at short notice;
- Avoiding all jargon and acronyms;
- Not assuming that everyone is computer literate/has easy access to a computer;
- Feeding back to any lay participants of the outcomes of projects they've participated in, and how their contribution was valued;
- Communicate the difference people have made;
- Ensure "clarity and transparency, from the start, in all communications."<sup>xiii</sup>

### 6. We will facilitate a service user-led process

We will seek to engage people who face equality or other barriers or those who may be excluded in some way, or those who face communication issues. The evidence<sup>xiv</sup> shows that service users often really value meetings led by service users<sup>xv</sup> and in many instances “peer-to-peer” participation is preferential.

We will endeavour to:

- Work with partners in the voluntary and charity sector to support peer-to-peer engagement and participation where relevant;
- Use different forms of involvement, including outreach, development, and advocacy<sup>xvi</sup> to ensure that we are as inclusive as possible;
- Promote the role of patient leaders – people; who want to lead change, transform the system, and improve the health and well-being in their community<sup>xvii</sup>.

*“When patients can lead and manage their own health and well-being and when they have developed the confidence and skills to lead and influence others, something special happens!”<sup>xviii</sup>*

“Bring it on – 40 ways to support patient leadership”, Centre for Patient Leadership

### 7. We will think beyond the meeting and provide a range of ways to participate

We acknowledge the complex/busy lives of people who live and work in North West London.

We will endeavour to:

- Provide a range of ways to get involved in our work, from “light touch” information and comment sharing (eg: twitter group) to more intensive working groups (eg: co-design, development and implementation);

- Explore opportunities for outreach and peer-to-peer engagement wherever possible to ensure that we are as inclusive as possible;
- Find out how everyone felt about the process and experience of participating;
- Evaluate how inclusive and diverse our participation has been.

As Peter Beresford comments in *Beyond the Usual Suspects* <sup>xix</sup>:

*“Service users also stress the need to develop innovative approaches to involving people which can work for the widest range and move beyond traditional reliance on meetings and surveys, written and verbal skills. They prioritise developing a variety of methods of involvement that can work for different people and are based on different forms of communication. They highlight the helpfulness of meetings and activities that are organised by service users and/or are for service users only, offering them safe opportunities to develop their ideas and agenda.”*

Peter Beresford, Director of the Centre for Citizen Participation

*“There is an opportunity to think differently, be open to new ideas, ask people to help solve your problems”*

Clive Mitchell, Programme Manager at Involve

## Tool for participation and co-design

### Introduction

We also wanted to design an online, interactive tool to support our partners, project managers and stakeholders to embed the principles for patient participation and co-design. To create the tool, we drew on theory and evidence from desktop research and advice from our stakeholder interviewees.

### Advice from interviewees

Interviewed stakeholders advised the following principles should be included in ICHP's tool for participation and co-design. These also align with the key ingredients identified by the Canadian cited earlier. <sup>xx</sup>

#### Recruitment of people with personal experience and structured preparation:

- Consider the role of information and evidence - sometimes evidence is different, for example perception of a high crime rate versus crime statistic, or perception that a school is failing but the evidence is that it's not;
- Make sure that providers of services are coming to the conversation in a prepared way;
- Share information.

#### Recruitment of a balanced group:

- Tap into social networks;
- Acknowledge where your expertise begins and ends;
- Just do it!

#### A combination of participation activities and group focused moderation:

- Follow a process to arrive at method;
- There are points when you need a smaller group to do more detailed work;
- There are points when you want to ask people specific questions and insights.

#### Engagement of people in the intervention design:

- For involvement to be meaningful, it needs to be from beginning to end;
- Be clear about purpose and recruit via partners – Trusts, lay members, patient participation groups, Healthwatch, voluntary organisations;
- Recruit patient and lay advisors to act as informed critical friends in early programme discussion and design.

## The theory and evidence that supports the tool

### 1. Scope and purpose - clearly describing what we want to achieve by involving service users and carers

*“Be really clear about roles that people are there to do, what’s in it for them.”*

Alison Baker, Lay member, NHS Hounslow CCG

*“One criteria to constantly bear in mind – value people’s time.”*

Michael Morton, Governing body lay member, NHS Central London CCG

Perhaps the most crucial stage of the participation and co-design process is the development of a shared purpose<sup>xxi</sup>. A purpose should not be assumed or unspoken, because different people with an interest or influence over the process can have a different agenda.

Participants may come to the process with very different perspectives. Plan to allow time for participants to communicate their experiences and develop shared understandings.

### 2. Finding the right participants can help to ensure that the process works well

*“People can bring insights from their working life as well as personal. People give their time, skills, knowledge and have leadership roles.”*

Varsha Dodhia, Founder of [NamasteCare.co.uk](http://NamasteCare.co.uk)

*“Plugging into patient leaders and groups that bring a different perspective, bring them right into the process of design and policy making as an expert resource.”*

Clive Mitchell, Programme Manager, Involve

Programmes would benefit from a preparatory phase, involving service users, which opens up possibilities for how people could participate and what they could offer. This would also enable an opportunity to ask service users what they would like to do.

As an organisation with no direct access to service users, ICHP is exploring a number of channels through which to recruit service users and the public for participation and co-design activity. Many interviewees referred to the scale of this challenge in terms of the demographics of the population in North West London.

Recruitment will depend on the role that we would like participants to play in the process. It is essential to make the selection process as transparent as possible.

People can also be accessed through community networks, voluntary groups, umbrella groups, community voluntary society, user led organisations. There is potential to use health specialist recruitment companies as they offers a good spread of people, new perspectives. There is also potential to develop a “people bank,” but many acknowledge that this takes time and resource, to build and maintain.

There is an emerging consensus that people should be paid to participate. This is a complex area and needs careful consideration. At the very least, people should be offered expenses in advance/travel booked on their behalf.

### 3. Reaching excluded or 'seldom heard' service users:

It is essential that those involved in the participation represent the population groups that the changes will have the greatest impact on. ICHP and partners serve a diverse population group and special efforts must be made to encourage the participation of excluded and seldom-heard groups.

This includes people who might face equality or other barriers (on the basis of gender, ethnicity, culture, belief, sexuality, age, disability and class) or may be excluded in some way (homeless, living in residential services, in prison, travellers), or those who face communication issues (deaf people, blind people, people for whom English is not their first language). For useful guidance on this see: <http://www.shapingourlives.org.uk/ourpubs.html>

*"We are working as equals, it is done with purpose, we have diminished the hierarchy."*

Varsha Dodhia, Founder of [NamasteCare.co.uk](http://NamasteCare.co.uk)

### 4. Choosing the right participation or co-design technique

*"The danger of co-production is that it is consultation re-branded. The challenge is to make it a way of working, a culture from beginning to end. It is a spirit that runs through everything you do."*

Tom Hoy, Partner at Stripe Partners

*"Our experience suggests that you need to take time to understand what experiences people may already have in order to identify how they can most usefully work together."*

Rachel Matthews, Patient Engagement lead for Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for North West London

A clearly defined purpose will make the decision about which co-design or participation techniques to use more straightforward.

All methods have their strengths and weaknesses and the key is to select the right one for the particular purpose and context, rather than to choosing one method as a 'favourite' and using it all the time. You may combine several methods.

## 5. The importance of communication

*“Create an environment where human beings talk to other human beings.”*

Raza Griffiths, Service user campaigner and trainer

Everyone interviewed stressed the need for regular, timely, respectful, and effective communication between programme leads and the participants.

Once the findings of the process have been analysed and taken forward, giving feedback to participants is crucial. Without clear feedback on the findings and how they were analysed and used, participants are likely to feel that their input was not valued.

## 6. Planning for review and evaluation

Defining the intended outputs and outcomes is a crucial element to the planning process and can form the basis for ongoing evaluation. It helps to plan to feedback to participants how successful the engagement was in developing outputs and achieving outcomes.

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.

*“Engaging citizens in co-producing health and wellbeing can help services tackle health inequalities by improving connections with less advantaged groups and by shaping provision to better meet community needs.” xxii*

Engaging the Public in Delivering Health Improvement, Leeds Metropolitan University

## Structure for ICHP participation and co-design tool

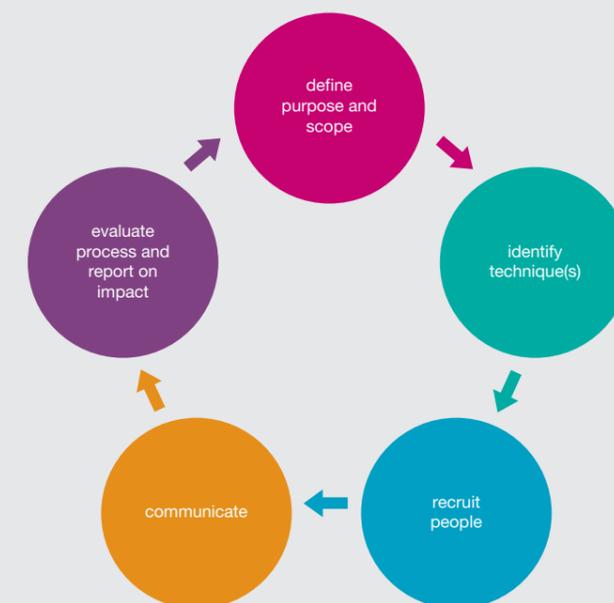
ICHP it is important for participation and co-design to operate at two levels: corporate and programme.

- At **corporate level**, participation will be about involving citizens and service users in decisions about the planning, design and delivery of ICHP.
- At **programme level**, participation and co-design will be about involving service users and carers as experience experts.

The following visual describes a process that could be followed for both programme and corporate participation.

The context would be a continuous process of learning and improvement.

- **Scope and purpose** - clearly describing what we want to achieve by involving service users and carers and linking this activity to corporate and programme goals
- Finding the **right participants**, in particular, reaching those that the programme will impact on the most, with special attention to excluded or ‘seldom heard’ service users
- Choosing the right participation or co-design **technique**
- Ensuring regular, timely, respectful, and **effective communication** between programme leads and the participants
- Planning for review and **evaluation** and adding to the evidence base for participation.



## The tool

The insights, advice and findings from our desktop research and stakeholder interviews have now been used to create the Patient and Public Participation Tool, which incorporates the agreed ICHP principles for participation and co-design. The aim of the tool is to take best practice, evidence and theory and translate these into an online, accessible tool for our project managers, partners and stakeholders to use, to help them assess how best to involve patients and the public, depending on what their goals are.

View the [Patient and Public Participation Tool](#) online.

*“Be clear about why we want this, what value will it add, what benefits will it bring for the member of public as well, there has to be something in it for them.”*

Victoria Thomas, Associate Director of the Patient and Public Involvement Programme, National Institute for Health and Clinical Excellence (NICE).



## Conclusion

We have now gathered a wealth of intelligence about patient and public participation from our own desktop research into best practice, as well as interviews with a range of expert stakeholders. Using the insights from this work, we have developed a set of agreed principles for patient participation and co-design. These state that we will:

- Approach participation and co-design from the perspective of service users and carers
- Reward service users and carers for their contribution
- Ensure there is clarity of purpose
- Create a space for equal partnerships between professionals and the public
- Carefully consider how we communicate
- Facilitate a service user-led process
- Think beyond the meeting and provide a range of ways to participate

To support the embedding of these principles in our own work and that of our partners and stakeholders, we have developed the online, interactive [Patient and Public Participation Tool](#). The tool is designed to support our project managers, partners and stakeholders to use best practice and learning from others, when deciding how to involve patients and the public in their work. We will continue to monitor and evaluate the use of the tool on an ongoing basis, and use feedback from our partners to help shape any further development needed in future.

# Appendices

## Appendix 1 - Transforming Participation in Health and Social Care

NHS England developed Transforming Participation in Health and Care (September 2013), to support clinical commissioning groups (CCGs) and other commissioners of health and care services to involve:

- Patients and carers in decisions relating to care and treatment.
- The public in commissioning processes and decisions.

The report can be accessed online at <http://www.england.nhs.uk/ourwork/patients/participation/>

In the report, NHS England has described the Ladder of Engagement and Participation:

There are many different ways in which people might participate in health depending upon their personal circumstances and interest. The 'Ladder of Engagement and Participation' is a widely recognised model for understanding different forms and degrees of patient and public involvement, (based on the work of Sherry Arnstein). Patient and public voice activity on every step of the ladder is valuable, although participation becomes more meaningful at the top of the ladder.

### Devolving

Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets or a community development approach.

### Collaborating

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

Working 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

Obtaining community and individual feedback on analysis, alternatives, and / or decisions. For example surveys, door knocking, citizens' panels and focus groups.

### Informing

Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities, solutions. For example, websites, newsletters and press releases.

## Appendix 2 - List of interviewed stakeholders

Name	Job Title	Organisation
Adrian Bull	Managing Director	Imperial College Health Partners
Alison Baker	Lay member, Chair of PPE Committee	NHS Hounslow CCG
Amy Darlington	Director of Communication and Engagement	Imperial College Health Partners
Anthony Okoro	Project Manager	Imperial College Health Partners
Axel Heitmueller	Director of Strategy & Commerce	Imperial College Health Partners
Camilla Sheldon	Head of Neighbourhood Community Budgets	Department of Communities and Local Government
Clive Mitchell	Programme Manager	Involve
Jeremy Taylor	Chief Executive	National Voices
Jonathan Weber	Vice Dean (Research) & Director of Research	Faculty of Medicine, Imperial College London Imperial College Healthcare NHS Trust
Josephine Ocloo	Consultant	Imperial College Health Partners
Jude Greenwood	Executive Assistant & Office Manager	Imperial College Health Partners
Lisa Hammoum	Admin Assistant	Imperial College Health Partners

## Appendix 2 - List of interviewed stakeholders

Name	Job Title	Organisation
Lis Paice	Chair	North West London Integrated Care Programme
Markella Boudioni	Patient and Public Involvement Manage	Patient Experience Research Centre (PERC) & NIHR Imperial Biomedical Research Centre (BRC), Imperial College London
Maurice Hoffman	Vice Chair - Harness Locality Patient Participation Group	NHS Brent CCG
Michael Morton	Governing Body Lay Member	NHS Central London CCG
Natalie Hudson	Communications Manager	Imperial College Health Partners
Olga Leonova	Project Manager	Imperial College Health Partners
Paula Murphy	Director	Healthwatch Central West London
Paul Hodgkin	Founder and chair	Patient Opinion
Phoebe Robinson	Head of Project Development and Performance Management	Imperial College Health Partners
Rachel Matthews	Theme Lead Patient and Public Engagement and Involvement	National Institute for Health Research Collaboration for Leadership for Applied Health Research and Care

## Appendix 2 - List of interviewed stakeholders

Name	Job Title	Organisation
Raza Griffiths	Consultation, Training and Events Officer National Involvement Project	NSUN Network for Mental Health
Robert Rutherford	Principal Research Officer	Department for Communities and Local Government
Ronke Akerele	Director of Programmes, Change and Performance	Imperial College Health Partners
Shane DeGaris	Chief Executive	Hillingdon Hospitals NHS Foundation Trust
Simon Denegri	Chair (Involve) National Director for Patients and the Public (NIHR)	INVOLVE NIHR
Simon Roberts	Founding Partner	Stripe Partners
Tom Hoy	Director	Stripe Partners
Varsha Dodhia	Lay Partner	ONWL Whole Systems Integrated Care Programme
Victoria Thomas	Associate Director: Public Involvement Programme	National Institute for Health and Care Excellence (NICE)

## Appendix 3 - Interview Questions – Imperial College Health Partners

### Preamble

Imperial College Health Partners has a diverse, complex, and vast work programme underway to support the discovery of new ideas and innovations, reduce unwarranted variation, and spread best practice. The involvement of service users and citizens in our work is crucial given they are the ultimate beneficiaries. We are therefore undertaking an important piece of work to explore how we can work in genuine partnership with people who use health services and live in North West London.

Our aim is to design a framework of patient and public participation and co-design that will enable people who use health services and live in NW London to participate in programmes that will impact on them, build capacity and capability within Imperial College Health Partners to enable participation and demonstrate that it has made a difference.

The purpose of this conversation is to:

- Explore the context, challenges and opportunities;
- Ensure that the plans are workable and meet shared objectives;
- Work out the detail for how a framework will be developed and delivered.

### Questions

The interviews will be informal discussions, allowing for individuals to raise issues and challenges, whilst focussing on some key issues. Questions will be adapted accordingly for external stakeholders with a specific interest.

### Introduction

First of all, please can you tell me a little bit about yourself, your organisation, and your role? What has been your experience of Imperial College Health Partners (patient and public participation activities) to date?

Thinking about Imperial College Health Partners unique role in NW London, what would you see as the guiding principles for patient and public participation that they could have to underpin their work?

What is your understanding of the evidence base for patient and public participation? Do you have any suggestions for guidance and best practice that we should signpost to?

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There are a range of audiences that Imperial College Health Partners will need to engage with – which do you see as the most important/challenging/effective?

As Imperial College Health Partners is an organisation with no direct access to service users, do you have any suggestions for channels available to recruit patients and the public for participation activity?

We are keen to include a range of participation methods, from co-design to insight collection through focus groups along with the pros and cons of each activity. What are your preferred methods for participation?

What would you see as the advantages of each?  
... and the challenges?

The intention is that the completed framework will be used to commission a list of preferred suppliers that can be called upon to support with various participation activity if required. Do you have any suggestions for the preferred list of suppliers?

### **Summing up**

Is there anything we haven't covered?

Thank you and discussion about next steps/feedback etc.

## Additional references and tools

- i** [http://www.institute.nhs.uk/commissioning/tackling\\_tough\\_choices/an\\_introduction\\_to\\_public\\_value.html](http://www.institute.nhs.uk/commissioning/tackling_tough_choices/an_introduction_to_public_value.html)
- ii** <http://participationcompass.org/pages/index/about>
- iii** The Good Governance Standard for Public Services, The Independent Commission on Good Governance in Public Services. <http://www.opm.co.uk/publications/good-governance-standard-for-public-services/>
- iv** The NIHR CLAHRC for North West London is a five year nationally funded collaborative research improvement programme that will accelerate health research into patient care. <http://www.clahrc-northwestlondon.nihr.ac.uk/>
- v** <http://coproductionnetwork.com/page/measurement-and-evaluation>
- vi** [http://www.institute.nhs.uk/commissioning/tackling\\_tough\\_choices/an\\_introduction\\_to\\_public\\_value.html](http://www.institute.nhs.uk/commissioning/tackling_tough_choices/an_introduction_to_public_value.html)
- vii** The Good Governance Standard for Public Services, The Independent Commission on Good Governance in Public Services. <http://www.opm.co.uk/publications/good-governance-standard-for-public-services/>
- viii** What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation. The Milbank Quarterly, Vol. 92, No. 2, 2014 (pp. 319-350)
- ix** 4PI National Survivor User Network and National Involvement Partnership 4PI National Involvement Standards (NSUN 2013)
- x** 4PI National Survivor User Network and National Involvement Partnership 4PI National Involvement Standards (NSUN 2013)
- xi** Engaging the Public in Delivering Health Improvement – Research Briefing for Practice, Leeds Metropolitan University.
- xii** Boyle, D and Harris, H (2009: 11) The Challenge of Co-production: how equal partnerships between professionals and the public are crucial to improving public services, nef/NESTA; London, UK

- xiii** National Survivor User Network and National Involvement Partnership 4PI National Involvement Standards (NSUN 2013)
- xiv** Peter Beresford, Beyond the Usual Suspects: Towards inclusive User Involvement – Research Report.
- xv** <http://www.shapingourlives.org.uk/ourpubs.html>
- xvi** <http://www.shapingourlives.org.uk/ourpubs.html>
- xvii** <http://centreforpatientleadership.com/>
- xviii** <http://centreforpatientleadership.com/>
- xix** Peter Beresford, Beyond the Usual Suspects: Towards inclusive User Involvement–Research Report.
- xx** What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation. ANTOINE BOIVIN, PASCALE LEHOUX, JAKO BURGERS and RICHARD GROL. The Milbank Quarterly, Vol. 92, No. 2, 2014 (pp. 319-350)
- xxi** 4PI National Survivor User Network and National Involvement Partnership 4PI National Involvement Standards (NSUN 2013)
- xxii** Engaging the Public in Delivering Health Improvement – Research Briefing for Practice, Leeds Metropolitan University.