

Patient and Public Involvement and Engagement Strategy Document

1. The National Institute for Health Research (NIHR)

The National Institute for Health Research (NIHR) funds and co-ordinates research in the English National Health Service (NHS). It is funded by the Department of Health and aims to improve the health and wealth of the nation by supporting health care research. The NIHR provides the support and resources required to carry out health care research including infrastructure, research personnel and equipment costs.

2. Introduction to the NIHR Diagnostic Evidence Co-operative London at Imperial College

The NIHR DEC London is one of four national centres of expertise funded by the National Institute for Health Research. The Diagnostic Evidence Co-operatives (Leeds, London, Newcastle and Oxford) are a network of strategic partners and collaborators that collectively form a pool of expertise and resources for methodology research and evidence generation in medical diagnostics. Each DEC shares in the common goal to catalyse the generation of evidence for in vitro diagnostic tests whilst maintaining its own core focus.

“Achieving excellence in point of care diagnostics from product design to patient benefits.”

The NIHR DEC London is a partnership between Imperial College Healthcare Trust and Imperial College London. Our mission is to establish a benchmark of excellence for supporting the lifecycle of Point-of-Care diagnostics from product design to integration into clinical practice and finally the attainment of patient benefits.

To achieve this we aim to:

- i. Build a strong alliance of academia, clinicians, regulatory bodies, patient representatives, designers and industry;
- ii. Conduct world-class research into Point-of-Care diagnostic tests;
- iii. Work in collaboration with NIHR infrastructure, including other DECs, and the NHS to efficiently bring Point-of-Care tests into clinical practice.

Our focus is Point-of-Care (POC) in-vitro diagnostics (IVD).

These tests are termed point of care due to their ability to be performed at the patient’s bedside. These are tests that give rapid results that allow prompt clinical decisions to be made. These may be tests carried out in hospitals, GP practices, nursing homes or by patients themselves in their own home. In many clinical areas such as diabetes, point of care tests are already widely used. With advances in modern technology, there has been a rapid increase in the availability of such tests to inform screening, monitoring and diagnosis of diseases within clinical settings. However, their introduction into clinical practice is often delayed due to an inability to confirm usefulness and areas that innovation can bring greatest benefit to the NHS and patients.

3. PPI Objectives 1st April 2016 to 31st December 2017

The NIHR DEC London is committed to actively involving and engaging patients and the public as partners in the processes by which research is identified, prioritised, designed, conducted and disseminated. To achieve this, the NIHR DEC London has the following key objectives:

- i. To build and maintain a diverse core patient and public involvement (PPI) group with an interest on Point-of-Care in-Vitro Diagnostics (POC IVD)
- ii. To create a PPI structure and model to support DEC London research
- iii. To involve and engage patients in active projects
- iv. To map out the activities for involvement, participation and engagement (see table 1 for description) until December 2017.
- v. To disseminate findings through social media e.g. twitter, Facebook etc.

Table 1. Description of patient and public activities

Involvement	Members of the public collaborate with researchers to support the development and execution of research processes for projects within the NIHR DEC London.
Participation	Members of the public are recruited to take part in various methodology and clinical research study
Engagement	Members of the public support the dissemination of project output, information and knowledge to a wider audience.

4. Proposed PPI framework 1st January 2017 to December 2022

There will be two types of lay members (Lay Associates) at the NIHR DEC London Lay Advisors and Project Associates. The Board of Lay Advisors will support i) the development of PPI within the NIHR DEC London, ii) the recruitment of Project Associates - based on resources provided by researchers – and iii) the review of output for each specific project. On the other hand, Project Associates will work closely with researchers to support the creation and execution of research within each project.

5. Recruitment of new members

All members will be recruited using adverts for Lay Advisors or Lay Associates on INVOLVE's *People in Research* site. Links to this advert will be placed in appropriate resources (i.e. the NIHR DEC London's website, NIHR network resources such as websites and newsletters) to facilitate recruitment.

Recruitment of all Lay Associates will require an advert, a role description form, and an application form. Recruited Lay Associates will be required to complete/sign the following:

1. Application form
2. Lay Associates background form
3. Confidentiality agreement

Project Associates, upon recruitment and completion of all required documents, will be provided with plain English summaries of the project they have been recruited for. The People in Research advert will contain a short summary (which does not include any confidential information) to support the recruitment of Project Associates. Work allocation is based on member's preferences and experience in relevant clinical areas.

For specific projects, Project Associates will be expected to support the creation of research resources including (but not restricted to) patient information leaflets and questionnaires as well as executing activities such as engagement events or focus groups.

6. Process of incorporating PPI into DEC London research

	Action
1	Company approaches DEC London
2	Proposal created according to initial meeting(s) – includes plain English and PPI work package
3	Proposal sent to company
4	Company agrees to proposal and signs contract
5	DEC and project collaborators complete the following templates <ul style="list-style-type: none"> i. Role description ii. Advert for Project Associates
6	DEC London introduces the new diagnostic device to Board of Lay Advisors using <ul style="list-style-type: none"> i. Plain English summary ii. Role description form iii. Advert for Project Associate
7	Board of Lay Advisors provide feedback
8	DEC London reviews and incorporates feedback, as required
9	If many applicants with appropriate experience – informal interviews will take place to aid decision-making
10	Recruited Project Associate(s) to support project as stated in role description form (to the best of individual’s abilities) i.e. <ul style="list-style-type: none"> • Feedback on project strategy • Support creation of research resources • Review draft and final documents • Support planned dissemination (e.g. paper, press release etc.)

7. Action Plan for Implementation

- i. To map out the activities for involvement, participation and engagement until December 2017.
- ii. To build and maintain a Board of Lay Advisors with an interest in Point-of-Care In Vitro Diagnostics (POC IVD).
 - Actions:
 - i. Create a policy document (and upload onto website) containing information on specific activities and payment for Lay Advisors.
 - ii. Set up a process for recruiting Lay Advisors.
 - iii. Have quarterly meetings with Board Advisors to provide updates of projects and obtain support in further developing PPI-informed research.
- iii. To ensure Project Associates are a part of the research team for each project carried out at the NIHR DEC London.
 - Actions:

- i. Create a policy document (and upload onto website) containing information on specific activities and payment for Project Associates.
 - ii. Set up a process for recruiting Project Associates.
 - iii. Ensure the preparation of required documents to inform the recruitment and working process of Project Associates (i.e. role description form)
- iv. Produce a Continued Professional Development (CPD) framework to ensure that Lay Associates and researchers are able to receive required training to support their role in research carried out at the NIHR DEC London