

Overview

From time to time, the New Nicotine Alliance (NNA <http://nnalliance.org/>) is asked by researchers to help them with their research. This help may include, for example: providing advice on research design and measurements; steering group membership; promoting recruitment to studies; facilitating access to products; advising on non-technical research summaries; and collaborating on publications. This kind of activity is broadly labelled as **Patient and Public Involvement (PPI) in research**.

According to INVOLVE (www.invo.org.uk), patient and public involvement (PPI) in research means research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. It should happen at the earliest stage, and during as many stages as possible, of a research project.

INVOLVE

INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research, to support active public involvement in NHS, public health and social care research. It is one of the few government funded programmes of its kind in the world. As a national advisory group, INVOLVE's role is to bring together expertise, insight and experience in the field of public involvement in research, with the aim of advancing it as an **essential part of the process** by which research is identified, prioritised, designed, conducted and disseminated.

NNA

NNA has adopted a **'nothing about us without us'** approach to supporting research activities that are concerned with improving public health through greater understanding of 'new' (lower risk) nicotine products and their uses.

For NNA, it is important to be visible and approachable to research groups to: (a) support funders' and ethics committees' requirements that researchers engage people affected by their research; and (b) to reduce the risk of 'bad science', by actively engaging with researchers to ensure that they have considered the expertise, experience and viewpoints of users of lower risk nicotine products.

NNA is keen to be involved in proper participatory research and will collaborate with researchers by offering advice and consultancy. NNA does, however, protect its Trustees and Associates from becoming over-stretched or exploited. Much of NNA's advocacy work requires the commitment of personal time and resources and there is a need to prevent inadvertent excessive burden on members through additional responsibility for PPI activities.

As such, NNA has prepared a statement, in line with current principles of good practice on PPI outlined by INVOLVE (<http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/>), which covers both financial and non-financial expectations of research collaboration agreements, to: (a) support researchers, research managers, institutions and organisations proposing working with NNA in the preparation of their research proposals, protocols and research materials where PPI is concerned; and (b) protect individuals associated with NNA when they embark on PPI activities on behalf of NNA.

NNA statement, based on INVOLVE's principles of good practice

PPI is often identified as core (and as such fundable) component of an application for research funding and compliance with recognised standards, such as those by INVOLVE, is usually expected through a project or programme of research. We urge researchers to follow the guidance on participation in research issued by INVOLVE. It is already endorsed or embraced by many relevant research funders, such as National Institute for Health Research (NIHR) (which established and funds INVOLVE) <http://www.invo.org.uk/>, Medical Research Council (MRC) Clinical Trials Unit http://www.ctu.mrc.ac.uk/our_research/patient_and_public_involvement/, Cancer Research UK (CRUK) <http://www.cancerresearchuk.org/support-us/volunteer/patient-involvement-at-cancer-research-uk>, and includes provision of the following for anyone engaged in PPI activities by a research group:

Financial

- reasonable payment for preparation and participation time (e.g. time spent reviewing documents or attending meetings (or suitable honorarium));
- all travel costs, overnight accommodation and subsistence (i.e. food and drink);
- where appropriate, childcare or replacement carer costs;
- costs of a Personal Assistant or Support Worker;
- conference fees;
- administration costs – for example printing, telephone, postage, stationery and other equipment; and
- training.

Ideally, arrangements should be made for advance payment. If this is not possible, research teams should be able to demonstrate that they have mechanisms and systems in place to guarantee timely reimbursement.

Non-financial

- adequate time should be given to prepare (e.g. documents should be sent out in advance);
- documents should be provided in a format that is accessible by the individual concerned;
- reasonable adjustments should be made to enable participation (e.g. timing of meetings to take account of travel distance, time off work, etc.); and
- pre-agreement of hours to be dedicated to PPI on a given project and a plan of when these fit within the project timeline.

SUMMARY: On the basis of this statement, NNA is very willing to offer assistance and advice on research projects. Please contact us for further details or to discuss a project requirement.

NNA will review this statement periodically and in line with INVOLVE guidance.

