

# Experiences of working with the HIV community

Caroline A. Sabin

Professor of Medical Statistics and Epidemiology  
UCL, London, UK

## Two parts to my talk....

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1. Academic perspective – PPI
2. Adding the human touch – personal reflections

# What is PPI?

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- Public and Patient Involvement
  - NOT proton pump inhibitor
  - Payment protection insurance
  - Pulp and paper industry
  - Pixels per inch...

# What is PPI?

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- Research being carried out ‘with’ or ‘by’ members of the public (or community) rather than ‘to’, ‘about’ or ‘for’ them
- Not just about using patients as research participants
  - (qualitative research ≠ PPI)
- Can lead to improvements in the value of research that is undertaken
  - Helps researchers to identify and ask the right questions in the right way
  - Ensures that research is relevant
  - Provides support with dissemination of research findings to a wider audience

# National Institute for Health Research (NIHR) INVOLVE

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- Established in 1996, part of, and funded by, the NIHR, to support active public involvement in NHS, public health and social care research
- Acts as national advisory group to bring together expertise, insight and experience in the field of public involvement in research
- Impact of public involvement in research defined as:
  - “The changes, benefits and learning gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiatives”

# Breaking Boundaries strategic review

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Strategic review of public involvement in NIHR

**Vision:** A population actively involved in research to improve health and wellbeing for themselves, their family and their communities

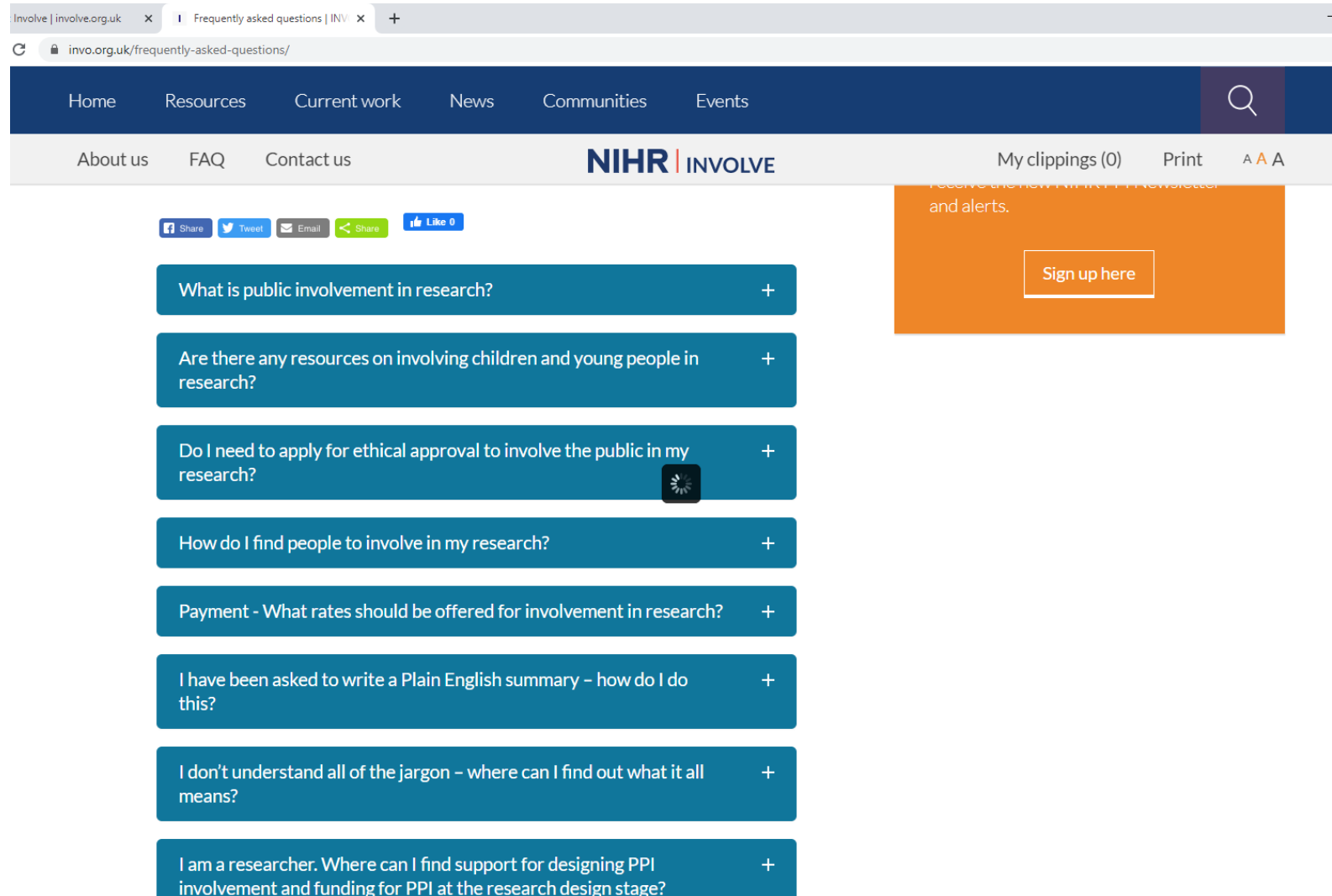


# Breaking Boundaries: Strategic goals for 2025

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1. Opportunities to engage and become involved in research are visible and seized by the public
2. The experience of patients, service users and carers is a fundamental and valued source of knowledge
3. Public involvement is a required part of high quality research conducted by researchers and their institutions
4. Public involvement is locally driven and relevant whilst strategically consistent with the NIHR's goals
5. Evidence of what works is accessible so that others can put it into practice
6. The NIHR has maintained its global presence and influence for working in partnership with the public

# NIHR INVOLVE

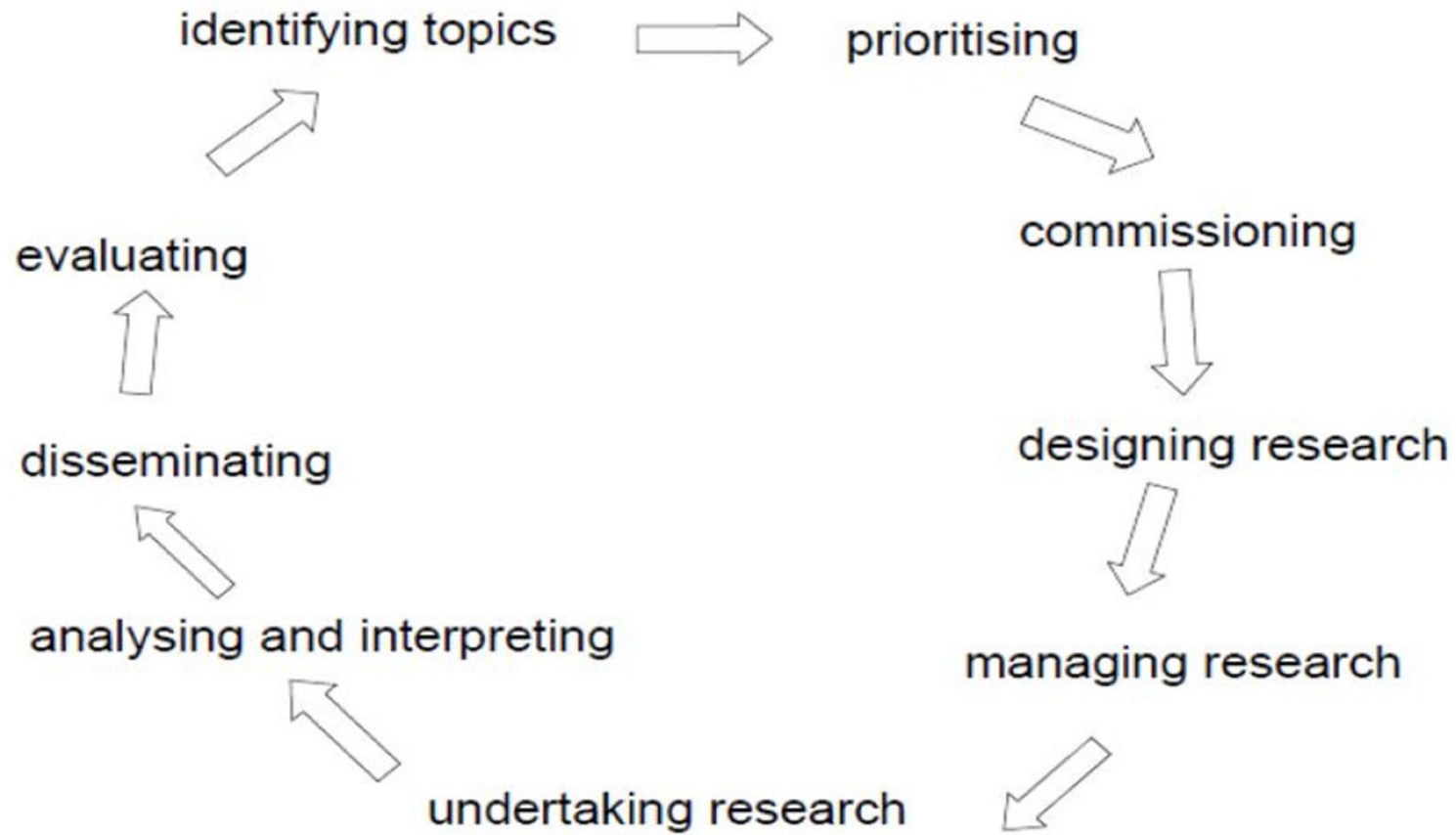


The screenshot shows the 'Frequently asked questions' page on the NIHR INVOLVE website. The page features a dark blue navigation bar with links for Home, Resources, Current work, News, Communities, and Events. Below this is a secondary navigation bar with links for About us, FAQ, and Contact us. The main content area is titled 'Frequently asked questions' and contains a list of eight questions, each in a blue box with a plus sign on the right to indicate it can be expanded. The questions are:

- What is public involvement in research?
- Are there any resources on involving children and young people in research?
- Do I need to apply for ethical approval to involve the public in my research?
- How do I find people to involve in my research?
- Payment - What rates should be offered for involvement in research?
- I have been asked to write a Plain English summary – how do I do this?
- I don't understand all of the jargon – where can I find out what it all means?
- I am a researcher. Where can I find support for designing PPI involvement and funding for PPI at the research design stage?

At the top of the page, there are social media sharing options (Facebook, Twitter, Email, LinkedIn) and a 'Like 0' button. On the right side, there is a search bar and a 'My clippings (0)' section. Below the clippings section, there is an orange box with the text 'Receive the new NIHR INVOLVE newsletter and alerts.' and a 'Sign up here' button.

# When to involve PPI?



# Key steps

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## 1. Allowing time for active involvement

- Involve people with personal experience from early stage
- Take account of diversity and equality
- Involve >1 person if possible
- Allow time to build relationships
- Offer choice about how people want to be involved

# Key steps

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## 2. Building respect and mutual understanding

- Reflect on value of everyone's time and experience
- Ground rules for meetings
- Consider diversity and cultural relevance

# Key steps

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## 3. Ensuring equal access to project activities

- Give clear, adequate and usable information in good time
- Plain language
- Plenty of notice for meetings (if possible)
- Meetings inclusive and in accessible venues
- Allow time for breaks
- Pay expenses promptly

# Key steps

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## **4. Offering continual support throughout research process**

- Informal chats/induction process
- Training/mentoring/guidance
- Establish community networks and communication links
- Offer support at end of involvement

# Key steps

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## 5. Considering methods of recognition

- Acknowledge contributions and thank people in person and print
- Consider value of people's time and offer payment as well as expenses (in cash if possible)
- Consider offering other benefits (training, support for attending conferences, co-authorship)

# Perceived challenges

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- Different priorities of community members from researchers
- Different models of working, arrangements for meetings etc.
- Takes too much time and effort – delays projects
- Requires too many resources
- Lack of importance/relevance, particularly for studies that are at a pre-clinical stage

# PPI for sexual health research

- Innovative and flexible approaches are required
- Traditional routes to PPI may be inappropriate
  - episodic infections
  - stigmatized behaviours/experiences
- Lay advisors offer lay perspective
  - Goal is not to seek full representation from target population
- Expand definition of ‘end user’ to include those with insight
  - e.g. professional proxies
- Provide variability regarding preferred means of communication and involvement
  - Including online and other remote means of conversing

**Education**

Collaborative and consultative patient and public involvement in sexual health research: lessons learnt from four case studies

Lorraine K McDonagh ,<sup>1,2</sup> Paula Blomquist,<sup>2,3</sup> Sonali Woyal ,<sup>2,4</sup> Sarah Cochrane,<sup>5</sup> Josina Calliste,<sup>2</sup> Jackie A Cassell,<sup>2,6</sup> Natalie Lois Edelman <sup>7</sup>

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/sextrans-2018-053922>).

For numbered affiliations see end of article.

**Correspondence to**  
Dr Lorraine K McDonagh,  
Research Department of Primary  
Care and Population Health,  
University College London,  
London NW3 2PF, UK;  
l.mcdonagh@ucl.ac.uk

**BACKGROUND**  
Patient and public involvement (PPI) refers to research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.<sup>1</sup> PPI can include patients, carers, service users and the public, referred to here as ‘lay advisors’ (can also be called PPI experts, public advisors, stakeholders, experts by experience). PPI entails contributing in varying degrees to the design, development, conduct, data analysis and dissemination of research.<sup>2</sup> Involvement can be consultative (single episode), collaborative (ongoing) or user controlled (actively controlled, directed, and

opinions (including backgrounds and experiences) should be sought. Lay advisors will have their own priorities and reasons for involvement, and as such a diversity in views will help ensure the research produced is holistic *and* that PPI activities are inclusive and meaningful rather than tokenistic.  
It may not always be possible to include potential end users if the population is particularly hard to reach (eg, prison populations, disenfranchised groups or social and cultural minorities). In such instances, it may be beneficial to engage instead with individuals who work with and so have insight into the target population, as was the situation in

# PPI in the HIV setting

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- Traditionally have had excellent community involvement in HIV research
  - People living with HIV as well as many other advocates
- Involvement of HIV community in research process itself through designing, managing, undertaking and disseminating good research
- Support from community members may help to:
  - Identify barriers to recruitment, particularly for traditionally under-served groups
  - Ensure that recruitment procedures are sensitive to participant needs
  - Suggest changes to improve clarity and increase participation
  - Ensure that language is appropriate and sensitive
  - Pilot questionnaires and review patient information sheets


## D:A:D study

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- Steering Committee and the D:A:D Oversight Committee - Simon Collins, Tracy Swan, and others
- Community representatives were huge advocates of the study
- Also provided me with tremendous support during difficult meetings...

# D:A:D study

- ABC/MI findings
  - Initial analyses performed November 2006
  - Submitted for publication January 2008
  - Presented at CROI 2008
- Produced community FAQ document
- Worked with team to ensure Discussion was appropriately worded with sufficient caveats
- Supported educational work to increase awareness of ‘channelling bias’

Use of nucleoside reverse transcriptase inhibitors and risk of myocardial infarction in HIV-infected patients enrolled in the D:A:D study: a multi-cohort collaboration 

D:A:D Study Group\*

**Summary**  
**Background** Whether nucleoside reverse transcriptase inhibitors increase the risk of myocardial infarction in HIV-infected individuals is unclear. Our aim was to explore whether exposure to such drugs was associated with an excess risk of myocardial infarction in a large, prospective observational cohort of HIV-infected patients.

**Methods** We used Poisson regression models to quantify the relation between cumulative, recent (currently or within the preceding 6 months), and past use of zidovudine, didanosine, stavudine, lamivudine, and abacavir and development of myocardial infarction in 33 347 patients enrolled in the D:A:D study. We adjusted for cardiovascular risk factors that are unlikely to be affected by antiretroviral therapy, cohort, calendar year, and use of other antiretrovirals.

**Findings** Over 157 912 person-years, 517 patients had a myocardial infarction. We found no associations between the rate of myocardial infarction and cumulative or recent use of zidovudine, stavudine, or lamivudine. By contrast, recent, but not cumulative, use of abacavir or didanosine was associated with an increased rate of myocardial infarction.

Lancet 2008; 371: 1417-26  
 Published Online  
 April 2, 2008  
 DOI:10.1016/S0140-6736(08)60433-7  
 See Comment page 1391  
 See Correspondence page 1413  
 \*Members listed at end of report; see webappendix for members of the contributing cohorts—ATHENA, Aquitaine, AHOO, BASS, The Brussels St Pierre Cohort, CPCRA, EuroSIDA.

## UK CHIC study

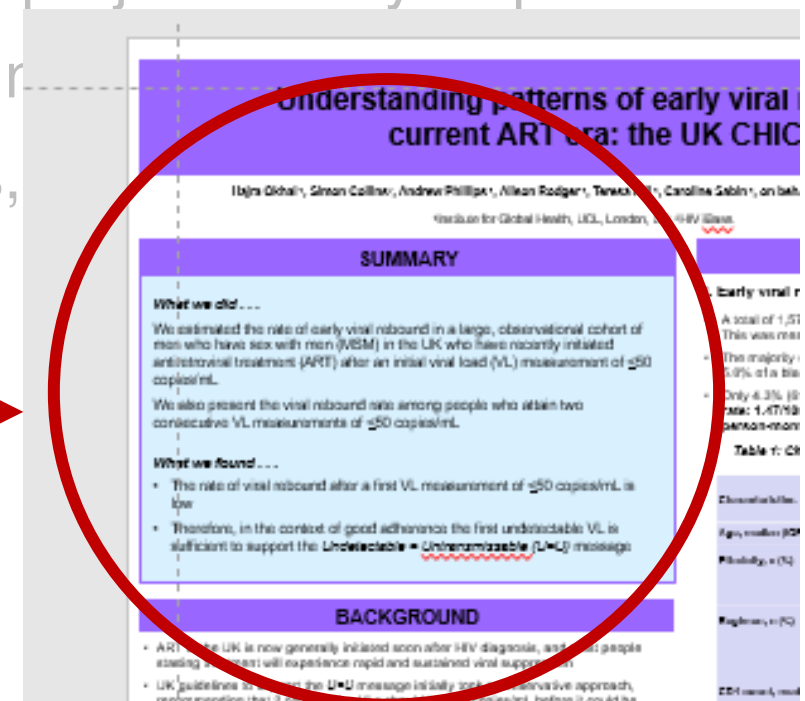
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- Simon Collins, Roy Trelvelion, Memory Sachikonye
- Patient survey around collection of potentially sensitive data
- Participate in discussions about ideas for future projects/analysis plans
- Contribute suggestions on behalf of the community
- Review all materials (grant applications, papers, abstracts)
- Presentations at annual meetings



# UK CHIC study

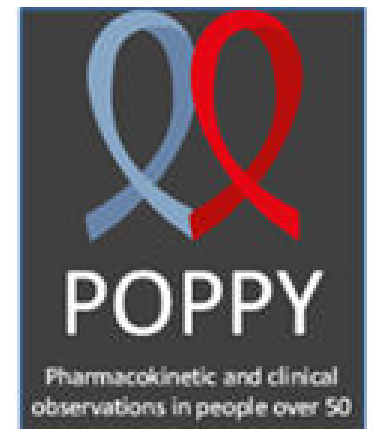
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- Contribute suggestions on behalf of the community
- Review all materials (grant applications, papers, presentations)
- Presentations at annual meetings
- Lay summaries for UK CHIC posters  
(P054 Okhai H *et al*)



# POPPY Study

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- Memory Sachikonye (with Roy Trelvelion for POPPY-pain)
- Involved with discussions around study design and content
  - Feedback to participants on BMD
  - Importance of studying ‘softer’ co-morbidities (e.g. mental health, pain, sleep...)
- Helped to develop study acronym
- Reviews all study materials, and pilots questionnaires
- Member of the Project Management Group to determine
- Support website design and reviews website materials
- Helps to arrange feedback meetings via UK-CAB
- Facilitate focus group discussions



# Inspiration for teaching


- Session on ‘Writing lay summaries’ inspired by Simon Collins (based on BHIVA presentation)
- Introduction to Flesch Reading Ease and Flesch-Kincaid Grade...

## A typical introductory paragraph

A Bear Called Paddington

by Michael Bond

Chapter One  
Please look after this bear



MR AND MRS Brown first met Paddington on a railway platform. In fact, that was how he came to have such an unusual name for a bear. for

Sentences per paragraph: 2.0  
Words per sentence: 4.5  
Characters per word: 5.2

Passive sentences: 0%  
Flesch Reading Ease: 70.6  
Flesch-Kincaid Grade Level: 4.5

# Summary – personal reflections

- My own research is enhanced hugely by community involvement
  - Keeps me focussed on the reasons why I am doing the research
  - Stops me slipping into bad habits re. language, use of terminology/jargon
  - Ensures I focus on the issues of greatest importance
- Yes it does sometimes add extra challenges...
- But it also adds an extra level of enjoyment to my life
- On behalf of myself and BHIVA – a BIG thank you to ALL of our community representatives

