

# Welcome to INVOLVE at 21

Sophie Ainsworth and Zoë Gray



# Plenary Speakers



- **Simon Stones** (Young Service User-Researcher and Generation R Member)
- **Laila Xu** (London YPAG member)
- **Anne MacKenzie** (Head, Consumer and Community Health Research Network, University of Western Australia)
- **Louise Wood** (Director of Science, Research and Evidence at the Department of Health)

# Housekeeping



# Emergency Procedures



- If there is an emergency you will be informed by an alarm notifying you that a situation is being investigated. Please stay where you are unless told to evacuate by a member of staff.
- In the event of a fire alarm an evacuation message will be sounded. Please follow the green fire exit signs to the Assembly Point in Deans yard.
- There is information in your conference guide on where the lunch will be served and location of the facilities.

# 1996



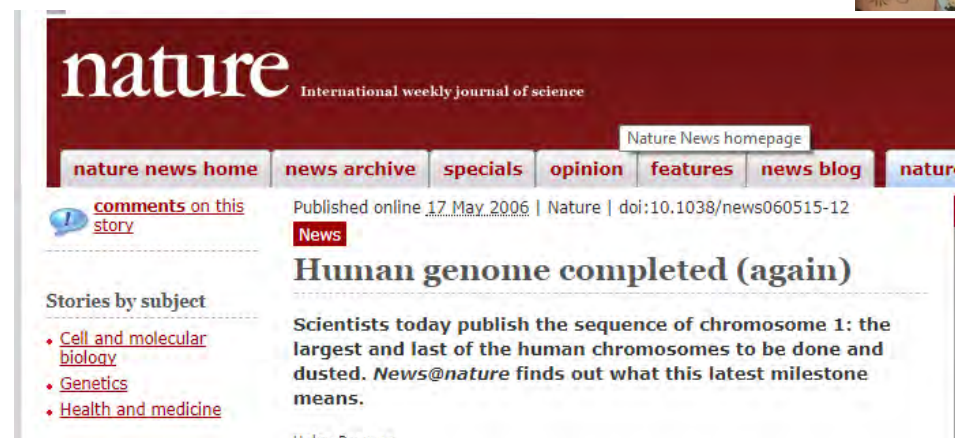
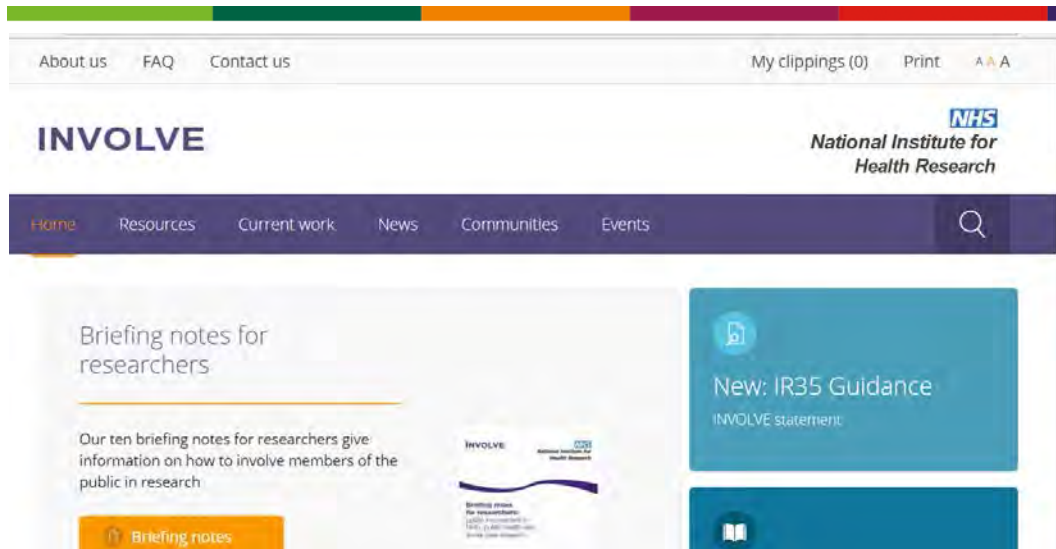
2004



**facebook**



# 2006





International Journal of Technology Assessment in Health Care, 27:4 (2011), 391–399.  
© Cambridge University Press 2011  
doi:10.1017/S0269462311000481

## The GRIPP checklist: Strengthening the quality of patient and public involvement reporting in research

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*University of Warwick*

Rosemary Barber

*University of Sheffield*

**Objectives:** The aim of this study was to develop the GRIPP (Guidance for Reporting Involvement of Patients and Public) checklist to enhance the quality of PPI reporting.

**Methods:** Thematic analysis was used to synthesize key issues relating to patient and public involvement (PPI) identified in the PIRICOM and PAPIRIS systematic reviews.

These issues informed the development of the GRIPP checklist.

**Results:** The key issues identified included limited conceptualization of PPI, poor quality of methods reporting, unclear content validity of studies, poor reporting of context and process, enormous variability in the way impact is reported, little formal evaluation of the quality of involvement, limited focus on negative impacts, and little robust measurement of impact. The GRIPP checklist addresses these key issues.

**Conclusion:** The reporting of patient and public involvement in health research needs significant enhancement. The GRIPP checklist represents the first international attempt to enhance the quality of PPI reporting. Better reporting will strengthen the PPI evidence-base and so enable more effective evaluation of what PPI works, for whom, in what circumstances and why.

**Keywords:** Patient and public involvement (PPI), Impact, Checklist, Reporting, Quality

Patient and public involvement (PPI) in Health Technology Assessment (HTA) and health research has become increasingly common internationally. Interest and activity have grown, with projects in the European Union, Australia, Canada, and other countries focusing on different aspects of PPI (1;3;6;11;14;18;20;21;24). There is a general agreement on the need for more patient-focused HTA methods

We would like to acknowledge the contribution of the research teams and advising groups for PIRICOM and PAPIRIS to these two original reviews. The PIRICOM systematic review was funded by the United Kingdom Clinical Research Collaboration. The PAPIRIS systematic review was funded by the National Centre for Involvement, UK.



# 2013



# 2014

'make it clear' campaign

make it  
clear





# 2015

## Going the extra mile:

Improving the nation's health  
and wellbeing through public  
involvement in research

The final report and recommendations  
to the Director General Research and  
Development / Chief Medical Officer  
(CMO) Department of Health of the  
'Breaking Boundaries' strategic review  
of public involvement in the National  
Institute for Health Research (NIHR)



# 2017



**INVOLVE** NHS National Institute for Health Research

**INVOLVE at 21**

Celebrate the progress of public involvement in research and consider the opportunities ahead.

Tuesday, 28th November 2017  
9:30 - 16:45

Church House, Westminster,  
London SW1P 3NZ

[www.invo.org.uk](http://www.invo.org.uk)



# INVOLVE's Vision and Mission

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The INVOLVE vision:



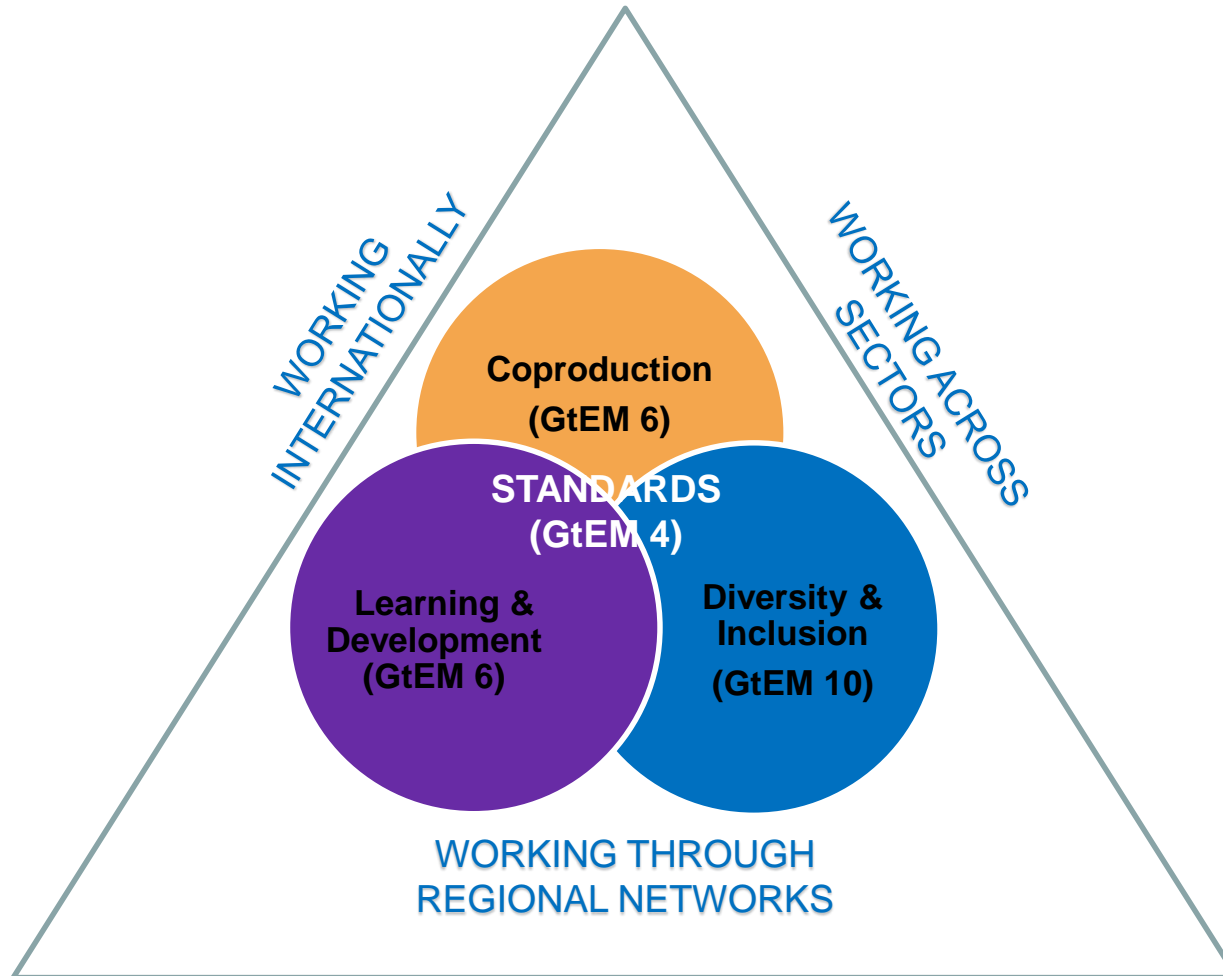
**A world of active public research partnerships leading to improvement of health and care for all.**

The INVOLVE mission:

**INVOLVE is the lead for advancement of public involvement in health and care research across NIHR and beyond. We achieve this by working with others to raise aspirations, drive up standards, provide guidance and facilitate partnerships.**



# INVOLVE's National Leadership Areas



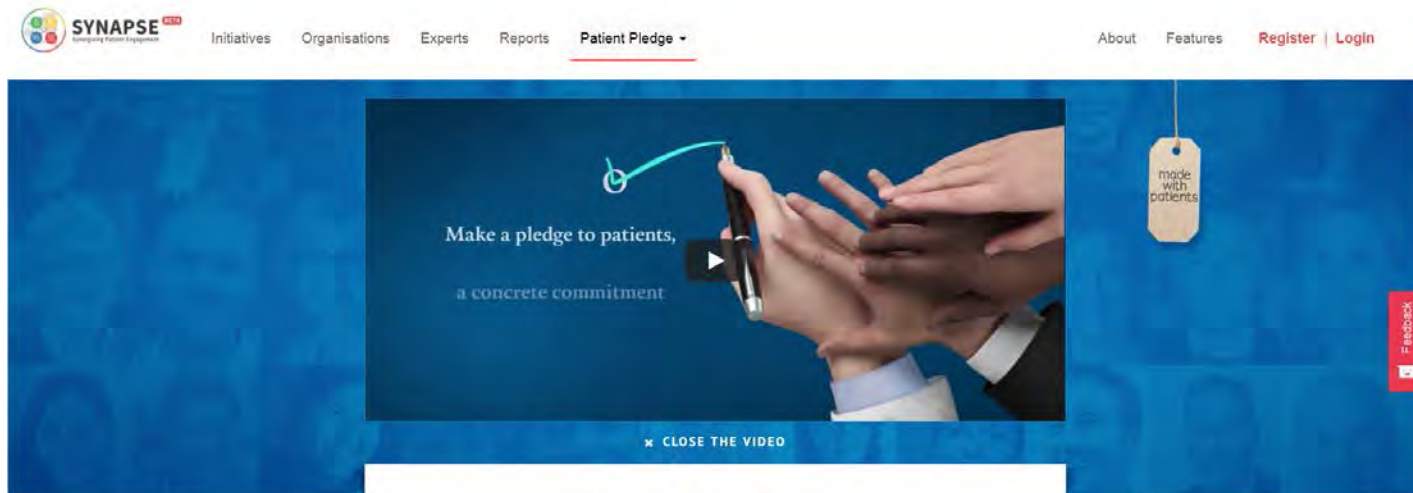
# Public Involvement Standards



Inclusive Opportunities  
Working Together  
Support and Development

Communication  
Impact  
Governance

# Pledges & Evaluation



## Sign the Pledge

Sign your pledge to patients and join our community and let's see how together we can progressively work towards effective patient engagement **by committing to systematically applying simple and sustainable patient-centered principles**, efforts leading to better patient and healthcare outcomes.



# In the next six months

I will work to make co-producing research as normal an approach to research as consultation and collaboration.'

Gary Hickey

I will strive to promote and support meaningful involvement of children and young people in research by working with them and researchers.

Kate Sonpal

I will create opportunities for all stakeholder voices to be heard and listened to in working group meetings, individual inquiries and through encouraging others to actively listen.

Paula Wray



# In the next six months

I will ensure that I use plain language in all my communications, and I will be more vocal in demanding that others use plain language when communicating with the public, colleagues and organisations.

Martin Lodemore



I will seek out and promote examples of great public involvement to inspire others

Sam Goold

I will influence others to consider and plan public involvement from the early stages of the development of new NIHR initiatives.

Zoë Gray

# Going the extra miles together: a mega-colony for public involvement!

