NIHR | Applied Research Collaboration East of England

Ethics of Involvement – Patient and Public Contributors, Monday 18th March 2024

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Ethics of Involvement – Patient and Public Contributors

3 x 15-min presentations + 30-min discussion:

- **‘You don’t need permission’**
- **‘Agency, Agency and Agency’**
- **‘You are not alone’**

‘You don’t need permission’

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.....to think ethically. In fact, you should!

There are ethical issues in every aspect of our lives, which we should think about

- Definitions
- Types of ethics
- Responsibilities

Ethics - definitions

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- Moral principles that govern a person's behaviour or the conduct of an activity
- How humans interact with each other
- Based on mutual respect & recognition of power dynamics or [im]balance & rightness / wrongness of certain actions

Four ‘branches’ of ethics

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- **Descriptive Ethics** is the study of people’s beliefs about morality
- **Normative Ethics** is the study of how people ought to act & standards for the rightness and wrongness of actions
- **Meta Ethics** is the study of what ethical terms & theories actually refer to, such as right or wrong, good or bad to evaluate human actions
- **Applied Ethics** deals with applying ethical attitudes and thinking to real life situations

Types of applied ethics in health & social care

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- **Medical ethics** – medical practice
- **Social care ethics** – social care practice
- **Research ethics** – research into human health or social care with human participants or identifiable data or clinical material
- **Ethics of public involvement**

Research ethics

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- Declaration of Helsinki
  - statement of ethical principles for medical research involving human participants, including research on identifiable human material and data
- Not all research, nor all health & social care research
- Research ethics is specifically about ‘protecting’ participants in research [into human health…]

Ethics of public involvement

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- Not a ‘formal’ discipline
- Related to research & research ethics
- Research ethics doesn’t apply to involvement in study design
- Ethical issues from ‘co-research’ included in ethical review of study

Small group discussion question

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How do you view your own responsibilities for thinking about ethics and ethical issues in your work and your personal life?

‘Agency, Agency and Agency’

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- The roles & responsibilities of individuals and organisations
- Researchers & Chief Investigators
- Research Ethics Committees (RECs)
- NHS RECs vs Institutional Review Boards (IRBs)


JESSIE Willcox Smith.

Responsibility for good ethical practice – You!

- We are all responsible for our actions and the way we interact with our fellow humans in all walks of life
- Do as you would be done by
- Design and conduct the studies you would consent to take part in

Principle 3: Scientific and Ethical Conduct
Research projects are scientifically sound and guided by ethical principles in all their aspects.

Principle 4: Patient, Service User and Public Involvement
Patients, service users and the public are involved in the design, management, conduct and dissemination of research, unless otherwise justified.

https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/uk-policy-framework-health-and-social-care-research/

Policy Framework for Health & Social Care Research

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- Chief investigators are responsible for the overall conduct of a research project, including satisfying themselves that the research proposal or protocol…makes effective use of patient, service user and public involvement…and is scientifically sound, safe, **ethical**, legal and feasible…

The Health Research Authority:

- Responsible for NHS RECs in England & other regulatory groups
- Works with Devolved Administrations to cover UK
- Not responsible for University or other RECs / IRBs

What do I need to do?

Last updated on 8 Jul 2019

Do I need HRA ethical approval before I work with patients and the public?

No. You do not need to submit an application to a Research Ethics Committee in order to involve the public in the planning or the design stage of research, even if the people involved are NHS patients.

Please note: Public Involvement does not refer to research participants taking part in a study. To find out which reviews your project needs, please use our tool.

You should describe how you plan to involve people in the management, conduct, analysis, or dissemination of your study in your application for Research Ethics Committee review, because doing so is likely to address ethical considerations which are of interest to the Research Ethics Committee. See best practice in public involvement principle 4.

PPI Ignite Network Statement on PPI and research ethics approval

Approval from a research ethics committee is not required for public and patient involvement (PPI) in the idea generation, planning, design, interpretation of findings, or dissemination stages of research.

During PPI, contributors are not research participants or data providers.

Disclaimer:

This information is for general purposes only. It is the responsibility of the research team to decide about research practices. They need to comply with research integrity obligations and ensure that ethical, data protection or safeguarding requirements are met. All principal investigators have a duty of care to members of their research team, including PPI contributors.

HRB Health Research Board

PPI IGNITE NETWORK

IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Small group discussion question

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What does good ethical practice look like where you work and in the work/activities you are involved in there?

‘You are not alone’

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- Working in partnership with people & communities
- Ethics of public involvement
- Responsibilities & approaches

Pandya-Wood *et al. Research Involvement and Engagement* (2017) 3:6
DOI 10.1186/s40900-017-0058-y

Research Involvement and Engagement

COMMENTARY Open Access

A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards

Raksha Pandya-Wood[1*], Duncan S. Barron[2] and Jim Elliott[3]

Paper based on issues raised in consultations between NIHR Research Design Service Public Involvement advisers and researchers.
Framework [for consultation] presents issues and possible solutions for use in practice.

A co-produced practice-based guide to ethical public involvement

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Ethics of Public Involvement in Research Design (EPIRD) Team:

- Duncan Barron, CPE, Kingston & St George's
- Jennifer Bostock, Public Contributor / NHS REC member
- Jim Elliott, Health Research Authority
- Lucy Frith, NIHR RDS North West
- Victoria Hamer, Public Contributor
- Julie Hapeshi, NIHR RDS South West
- Delia Muir, NIHR RDS Yorkshire & Humber
- Raksha Pandya-Wood, NIHR RDS East Midlands

Background to the paper

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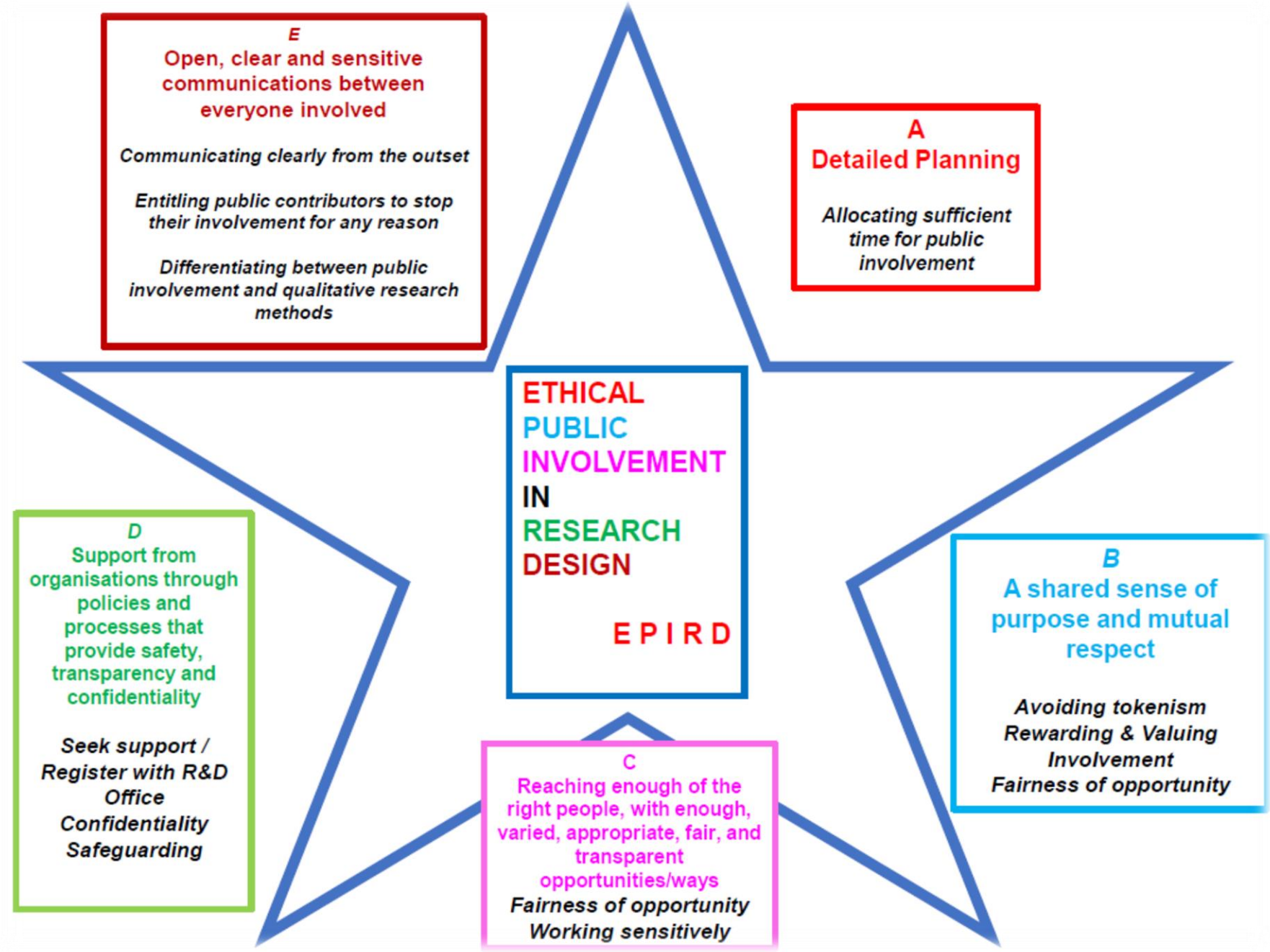
- First-hand experience on advising researchers at the research design stage (Duncan & Raksha)
- Presentation at the INVOLVE 2010 conference (framework comprised only 3 issues)
- Consultation workshops in the East Midlands separately with members of the public & researchers
- Lay input from 2 members of the public in developing the published draft framework into a practical tool


E
Open, clear and sensitive communications between everyone involved
Communicating clearly from the outset
Entitling public contributors to stop their involvement for any reason
Differentiating between public involvement and qualitative research methods
A
Detailed Planning
Allocating sufficient time for public involvement
ETHICAL
PUBLIC
INVOLVEMENT
IN
RESEARCH
DESIGN
E P I R D
D
Support from organisations through policies and processes that provide safety, transparency and confidentiality
Seek support / Register with R&D Office
Confidentiality
Safeguarding
B
A shared sense of purpose and mutual respect
Avoiding tokenism
Rewarding & Valuing Involvement
Fairness of opportunity
C
Reaching enough of the right people, with enough, varied, appropriate, fair, and transparent opportunities/ways
Fairness of opportunity
Working sensitively

Small group discussion question

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How might we work together to take forward the thinking about good ethical practice in public involvement in research?

Thank you for listening and engaging in the discussions

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If you would like to know more about the work and ideas presented or discuss it further, please contact:

Jim Elliott, on behalf of the Ethics of Public Involvement in Research Design Team, at drakesyard@gmail.com or see @drakesyard on Twitter (I know it now has the silly new name ‘X’ but I still call it Twitter)

Or

Jurgen Grotz, Senior Research Fellow, Director of the Institute for Volunteering Research and Research Fellow, NIHR - ARC East of England, at J.Grotz@uea.ac.uk

REC Membership

NHS Health Research Authority

Would you enjoy promoting ethical research by joining a Research Ethics Committee?

Further information about committee membership is available at:
www.hra.nhs.uk/join-a-REC

Thanks for listening

Any Questions ?