

# PPI in research: designing for impact



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# RATIONALE FOR REF

- To assess the quality of research.
- To inform funding allocations.
  - UK Gov Funds - £10 Billion 2015-2020
  - RCs, Charities, H2020 - £20 Billion 2015-2020
- Provide accountability for public funding of research and demonstrate the public benefits. (IMPACT)
- To provide benchmarks and reputational yardsticks.



# What was assessed?

Panels judged the **overall quality** of each submission

**65%**

**Maximum of 4  
outputs per  
researcher**

**191,150** research  
outputs by **52,061**  
staff were reviewed

**20%**

**Impact** of research  
on society

**6,975** impact case  
studies were  
reviewed

**15%**

**The research  
environment**

The review was  
based on data and  
information about  
the environment

# REF2014: Research Impact

Impact defined broadly for the REF:

*an effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia*

Impact **includes** an effect, change or benefit to:

- the activity, attitude, awareness, behaviour, capacity, opportunity, performance, policy, practice, process or understanding;
- of an audience, beneficiary, community, constituency, organisation or individuals;
- in any geographic location whether locally, regionally, nationally or internationally.

## Research Impact: A case study approach:

- Academics to explain impact in their own terms
- Using quantitative and qualitative evidence as appropriate to the case being made
- 1 case study per 10 members of staff submitted
- Impacts that occurred during 2008-2013, underpinned by research since 1993
- Underpinning research must meet a quality threshold
- Research contribution not attribution
- Assessed jointly by academic and 'user' expert (e.g. Sally Brearley)

# Research Impact: Assessment

- Impact case studies and templates are judged according to:
- **Reach:** the extent and/or diversity of the organisations communities and/or individuals who have benefitted from the research
- **Significance:** The degree to which the impact has enriched, influenced, informed or changed the policies, practices, understanding or awareness of organisations, communities or individuals

# Impact Assessment Criteria

The criteria for assessing impacts are reach and significance\*

<b>Four star</b>	Outstanding impacts in terms of their reach and significance
<b>Three star</b>	Very considerable impacts in terms of their reach and significance
<b>Two star</b>	Considerable impacts in terms of their reach and significance
<b>One star</b>	Recognised but modest impacts in terms of their reach and significance
<b>Unclassified</b>	The impact is of little or no reach and significance; or the impact was not eligible; or the impact was not underpinned by excellent research produced by the submitted unit

\* Each main panel provides descriptive account of the criteria

# Research Impact: Examples

## Impacts on:

- Health and welfare
  - Society, culture and creativity
  - The economy
  - Commerce
  - Public policy and services
  - Practitioners and services
  - Environment
- International development

## For example:

Patient outcomes have improved  
Public debate has been stimulated  
Costs of healthcare have changed  
New health care products produced  
Health policy changed by research  
New professional standards  
Benefits to environmental health  
Quality of life improvements





# Some examples of impact

Improved health or welfare outcomes

Enhanced professional standards, ethics, guidelines or training

Improved risk management

Public debate has been shaped or informed by research

Improved quality, accessibility or efficiency of a public service

More effective management or workplace practices

Improved business performance

Changes to the design or delivery of the school curriculum

Production costs have reduced

Research has enabled stakeholders to challenge conventional wisdom

A social enterprise initiative has been created

Policy debate or decisions have been influenced or shaped by research

Enhanced preservation, conservation or presentation of cultural heritage

Improved access to justice, employment or education

Improved forensic methods or expert systems

Organisations have adapted to changing cultural values

Jobs have been created or protected

Research has informed public understanding, values, attitudes or behaviours

Improved management or conservation of natural resources

Enhanced corporate social responsibility policies

Levels of waste have reduced

The policies or activities of NGOs or charities have been informed by research

Changes to legislation or regulations

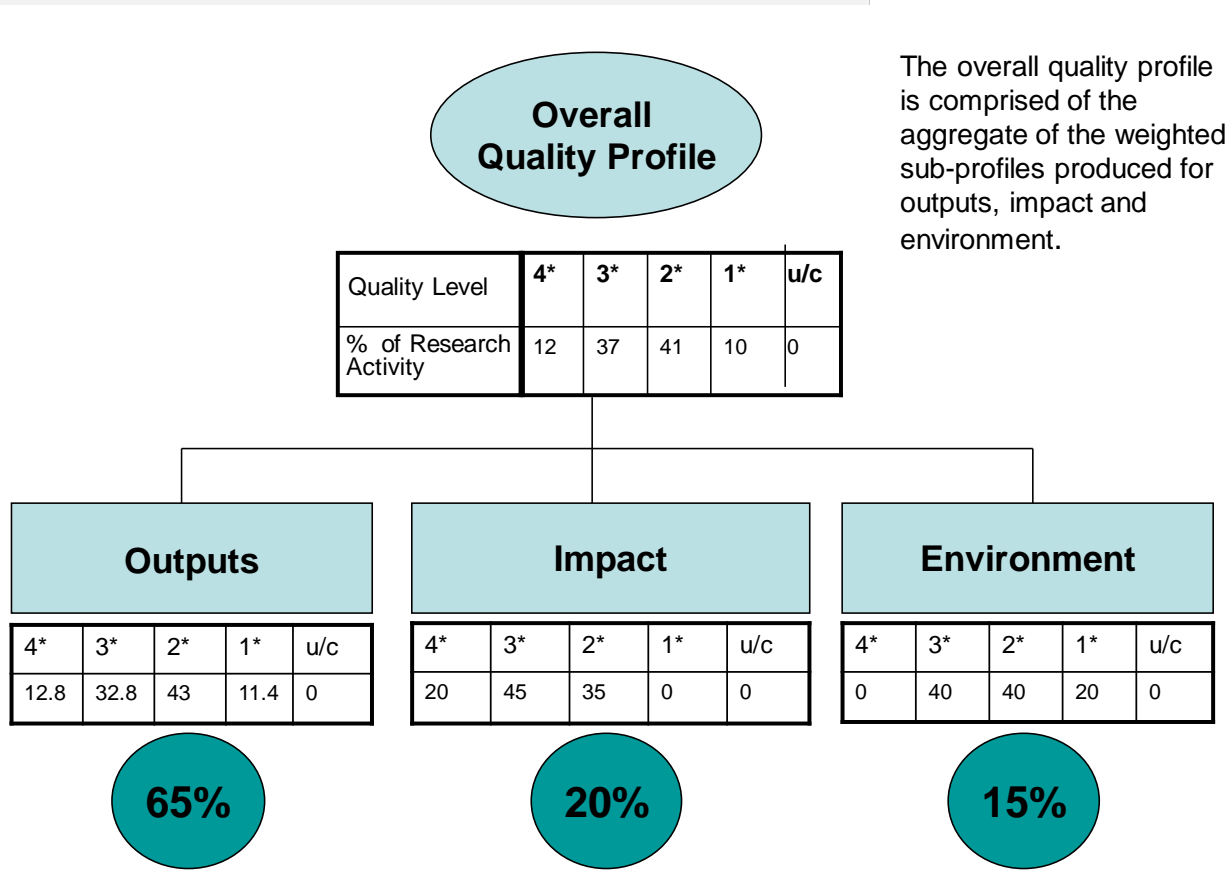
A new product has been commercialised

New forms of artistic expression or changes to creative practice

Changes in professional practice

Enhanced technical standards or protocols

# EXAMPLE OF A REF QUALITY PROFILE



# Research Impact -UK Results

- 44% of submitted impacts were judged to be 4\* (outstanding) and a further 40% were rated 3\* (very considerable quality).
- Impressive impacts were found from research in all subjects.
- UK Research has impact in ALL countries over the world
- REF shows many ways in which research has fuelled economic prosperity, influenced public policy and services, enhanced communities and civic society, enriched cultural life, improved health and wellbeing, and tackled environmental challenges.



# Research Impact: Passive to Pro Active

## Passive

- Research is done.
- Disseminated.
- It is found and used by others to have impact.

## Active

- Research is done.
- Identify some potential impact partners.
- Work with them to develop impact.

## Proactive

- Include partners (PPI) in the research design.
- Work with them to generate impact.



# Research Impact: Searchable Database

- Hearing the Voice of the User: Influencing Policy Through Participation
- Understanding and responding to user behaviour in ever changing information environments
- Empowering mental health service users
- Improving Engagement with Involuntary Service Users in Social Work
- Mental Health Research and Knowledge Exchange Group
- Care Transition Experiences: developing a user and carer centred approach
- Pioneering user engagement using digital methods
- The Recognition and Implementation of Improvements to Patient Dignity and Care

# PPI in Research: A moral imperative

- The NIHR (2012) advocated early involvement of patients are partners in research.
- This not only enables trust, but reduces the possibility of what Weinstein (2010) described as the “theft” or “piracy” of lived experience by researchers.



# PPI in Research



# Answers to free-text responses claiming to be involvement but not .....

**“patients will be involved during the research as subjects”**

**“I will be asking my patients to take part in my study”**

**“patients will be asked to carry the sampling storage equipment (bottles and paper) and present them to staff at delivery”**

**“dentists will provide feedback on the proposed interview guide”**

**“ participants will be offered a copy of the results of the study.”**

**“I will be giving talks about the research”**

**“ I see patients all the time, I know what their views are on this”**



# Answers to free-text responses accurately describing involvement:

**“the patient information sheets were written by a patient advisory group”**

**“service users helped develop the research topic and what research questions should be asked”**

**“named members of the public as co-applicants who will continue to be involved in the study”**

**“we have invited patients on the trial steering group/ management group”**

**“ the study was conceived, designed and being led by a patient group who have led the application for funding and will be involved in all aspects including undertaking the research and dissemination”**

# PPI and Research Impact

- The Nuffield Council on Bioethics argues that involving the public in research helps to ensure that research will then be better targeted to what society wants and needs.
- An increase in citizen science programmes about the environment has led to more public interest in environmental issues. Translating that to health research would see people getting more invested in their own health. (Erinma Ochu, 2015)
- Sometimes patients and the public, who don't know the patterns in data that academics have learned to see, might see something a little different that is meaningful and impactful.

# PPI and Research Impact

- **Prediction and management of cardiovascular risk for people with severe mental illness. PRIMROSE Programme.**
- **About the study:** To find ways to reduce cardiovascular risk in people with severe mental illnesses by developing an intervention for use in primary care. The findings have informed the design of the new intervention.
- **How service users and carers have been involved:** The research team includes a service user researcher who is employed via Rethink. Rethink have also set up a Lived Experience Advisory Panel (LEAP), which is a panel of service users and carers who help steer the project. Members of the panel have also joined an Intervention Development Group.
- **The impact of the involvement:** Service users and carers have had a major impact on the shape of the research project. They have also had a significant influence on the development of the new intervention and helped to identify ways to overcome barriers to its implementation.

(Kristina Staley, 2013)

# PPI and Research Impact

- **Shared Decision Making in Psychiatric Medication Management (The SHIMME study)**
- **About the study:** This study aims to encourage service users and clinicians to make shared decisions about medication (shared decision-making). Based on the findings the team developed parallel training programmes for the various stakeholders, as well as written materials to support a shared decision-making process. This intervention is now being tested and evaluated with an adult community psychiatric service in Cambridge.
- **How service users and carers have been involved:** Service users and carers have been involved at every stage of the project. They were involved in developing the research question and the funding bid, which took over two years.
- **The impact of the involvement:** There has been an impact on every aspect of the research and at every stage, from developing the idea for the project through to developing and testing the new intervention.

(Kristina Staley, 2013)

# PPI and Research Impact

- **Autism Spectrum Social Stories In Schools Trial (The ASSSIST Trial)**
- **About the study:** This study is developing an intervention based on Social Stories to support children on the autism spectrum in mainstream schools.
- **How service users and carers have been involved:** Parents were members of the Trial Management Group with responsibility for the day-to-day running of the project. They were members of an Expert Writing Group that developed the new manual and training package.
- **The impact of involvement:** Parents of autistic children provided momentum for the study, helped shape the project plan, contributed to writing the grant application and have been extensively involved in developing the intervention.

(Kristina Staley, 2013)

# PPI and Research Impact

- **Exploratory Randomised Controlled Trial of an Online Multi-component Psycho-educational Intervention for Siblings of Individuals with First-episode Psychosis (The E Sibling Project).**
- **About the study:** This study aims to develop online information and support for siblings who have a brother or sister with a first episode of psychosis.
- **How service users and carers have been involved:** Siblings have been involved via a Siblings Reference Group that was set up to help develop the project proposal and has had an oversight role ever since. A multi-stakeholder Expert Advisory Group that includes siblings, service users and parents advise on the development of the online resource.
- **The impact of involvement:** The siblings have helped to design the project, resolve some of the practical issues, helped with recruitment and contributed to the development of the intervention.

(Kristina Staley, 2013)

# PPI - Impact

## Impact on Study

- Identification of more meaningful research topics and questions.
- Increased number of patients participating in study,
- Richer Data
- More relevant and accessible findings
- Quicker dissemination and translation into appropriate and timely interventions.

## Impact on Society

- Greater trust in and acceptance of research
- Projects focused on benefits for the community
- New and improved services
- Changes in Practice
- Partnerships that can affect change.
- Improved relationships between communities and professionals

# Useful links and Reading

- INVOLVE [www.invo.org.uk](http://www.invo.org.uk)
- PCORI [www.pcori.org](http://www.pcori.org)
- SPOR [www.cihr.ca](http://www.cihr.ca)
- [www.sph.uwa.edu.au](http://www.sph.uwa.edu.au)
- [www.twocanassociates.co.uk/routemap](http://www.twocanassociates.co.uk/routemap)



## Further Reading

- Minogue V, Boness J, Brown A, Girdlestone J The impact of service user involvement in research. *Int J Health Care Qual Assur* 2005; 18: 103–12.
- Staley, K. (2013) *A series of case studies illustrating the impact of service user and carer involvement on research*, NIHR Mental Health Research Network: London
- Staley K. (2009) *Exploring Impact: public involvement in NHS, public health and social care research*. INVOLVE: Eastleigh.
- Ennis, L. & Wykes, T. (2013) Impact of patient involvement in mental health research: longitudinal study, *The British Journal of Psychiatry*,
- Brett, J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R. (2014) Mapping the impact of patient and public involvement on health and social care research: a systematic review *Health Expectations* Oct;17(5):637-50.  
doi: 10.1111/j.1369-7625.2012.00795.x. Epub 2012 Jul 19