



Doeth Am Iechyd
Cymru
HealthWise
Wales

HealthWise Wales

Your Health, Your Research

An Introduction

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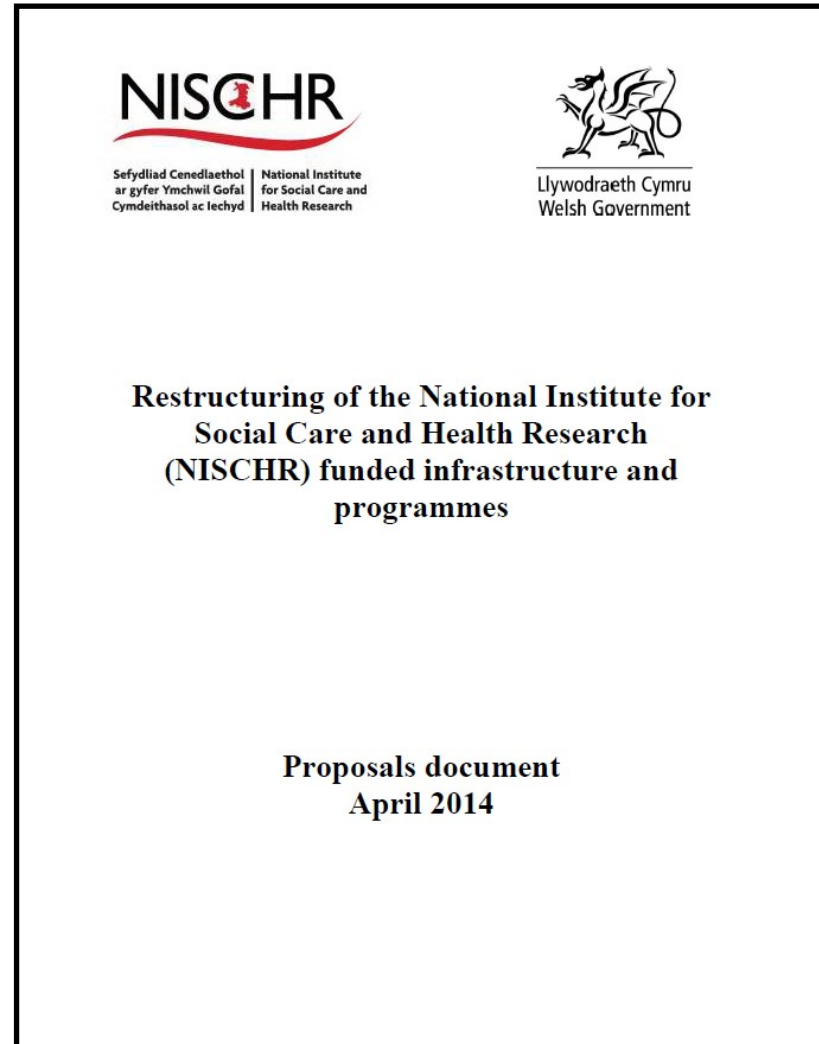
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Origin Story

➤ Restructuring document



Origin Story 2

“The next five year period for R&D in Wales will be driven by a new approach. This will put the citizen at the heart of creating new knowledge and putting new knowledge into practice. The NHS belongs to the people of Wales and they have a strong sense of ownership of everything that it does.

We intend to create a citizens’ cohort where all people in Wales will be invited to participate in research, to contribute their information to better inform new treatments, new services, new products and new processes.

This will be driven in a way that creates a new partnership between the population, users and researchers, ensuring effective consent, and a new level of transparency.”

NISCHR Restructuring Proposal Document, January 2014

Rationale

- Embedding a culture where contributing to research is something that is valued and something to be proud of.



Giving
Blood



Organ
Donation



Contributing
To
Research

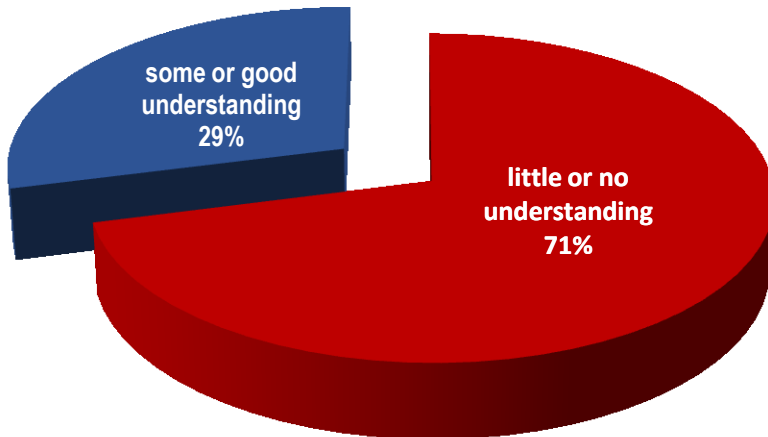
Public Understanding

- Beaufort Research report commissioned In October 2014
- Completed March 2015, published May 2015

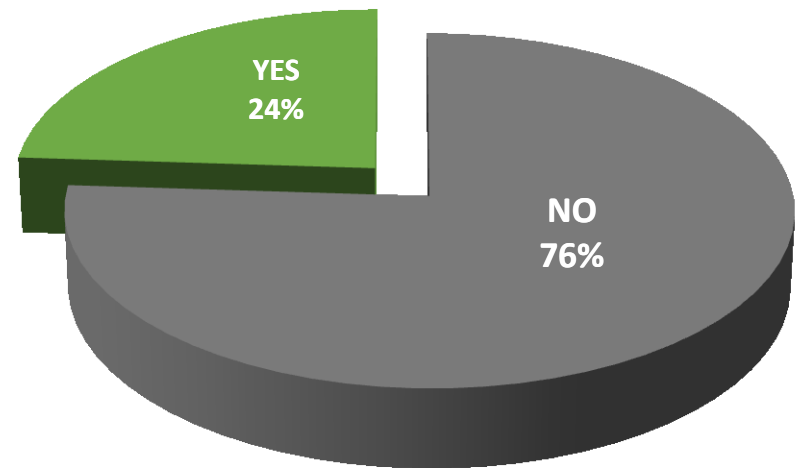


Current Awareness

Research Awareness



Personal Experience Of Research



Perceptions

“I’ve got a nephew, he went for a clinical trial and he turned yellow. Deeply yellow.”

“...not if it’s prodding and poking... Or, like, taking anything.”



Perceptions 2

“My brother is ill, so there is trials of a new tablet they are bringing out, so he did take that. So there is ill people who do these trials.”

“If it was someone who had no money or had trouble getting money they’d do it easy, they’d be straight down for it...”

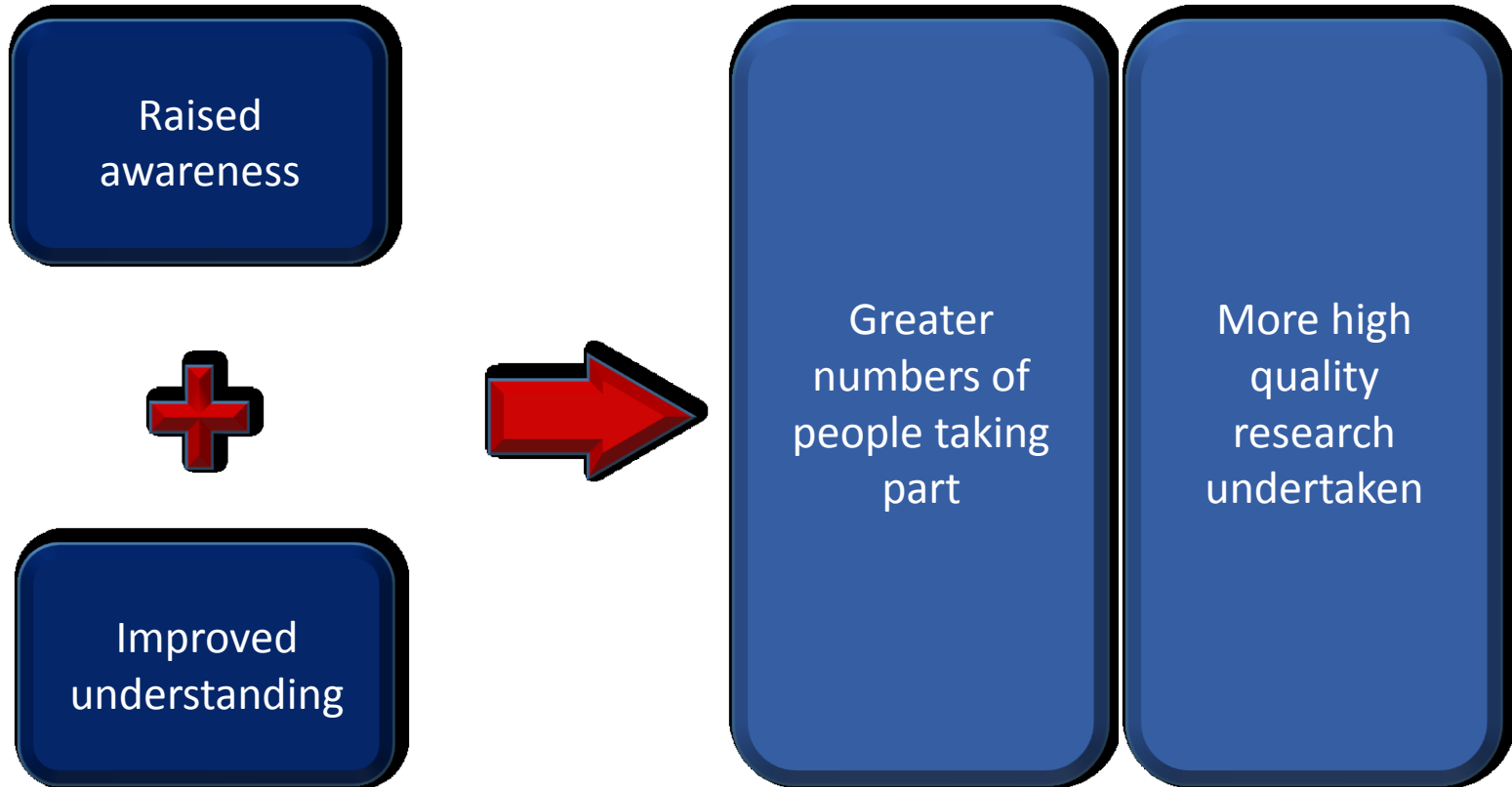


Positives!

- Once explained, people are very supportive of health and social care research (91%)
- Better awareness/understanding can generate some willingness to take part (48%)
- Strong agreement that everyone should be given the opportunity to take part (72%)



Where does this take us?



The role for HealthWise Wales

Aim

To increase awareness and enable people to contribute to research in a direct, valuable and straightforward way

- HealthWise Wales invites public to join and consent via web (or telephone), to contribute to:
 - Public/population health research programme (cohort) with consent to link to routine data – that is centred around a suite of dialogue and engagement mechanisms to ensure the public have an equal and active role in shaping the priorities and issues to be explored
 - Register of individuals who have agreed to be contacted about research opportunities relevant to them

HealthWise Wales Ambitions

- **To be people-centred**
 - Raising awareness, understanding and access to research
 - Opportunities for individuals to find studies relevant to them
 - To offer a platform to answer public health and health services questions, and for the public to be equal partners in the priorities and design of these questions
- **To create a research asset that demonstrates Wales as a premier destination for health & social care research**
 - A register of people willing to be contacted about research studies
 - Consented, linked participant reported and routinely collected data
 - Innovative platform for delivery of studies
 - Future expansion to provide richest cohort of data possible, including bio-sampling and genomic components

Development

- Task & Finish Group: public, academics, charities, NHS and social care representation
- Public steering group – 9 representatives from Involving People Network
- Over 1000 people contributed to qualitative and quantitative research
- Over 430 responses on the brand identity consultation

Development 2

- National advert and interviews for the HealthWise Wales Scientific Lead post
- Dr Shantini Paranjothy appointed as Scientific Lead
- 3 year grant to Cardiff University (including sub-contract with Swansea University)
- Protocol for HealthWise Wales received ethics favourable opinion in March 2015

HealthWise Wales Population

