fuse The Centre for Translational Research in Public Health

Newcastle University Institute for Social Renewal

involvenortheast involving people in health and wellbeing

Beyond tokenism: PPI with impact

Enriching patient and public involvement in public health research

Date: Thursday October 16th 2014
Time: 9:30-4:15
Venue: The Beacon Centre, Westgate Rd, Newcastle Upon Tyne, NE4 9PQ

A Fuse Quarterly Research Meeting planned with the Newcastle Faculty of Medical Sciences and Institute for Social Renewal, and Involve North East.

Why hold this meeting now?

Patients and the public are active participants in a broad spectrum of health research and reviews of research proposals. Funding bodies, such as the National Institute of Health Research (NIHR), increasingly require researchers to demonstrate how members of the public have been involved in the design and development of grant applications. From design through to dissemination of research, patients and the public are playing a bigger role, but how effectively? How do we know if it makes a difference, and for whom and how? What are the challenges? What can we do better? What have we learned? The meeting coincides with the NIHR strategic review of patient and public involvement **(**PPI): 'Breaking Boundaries: thinking differently about public involvement in research'.

This event aims to:

- Bring together and draw on the experience of researchers, carers, patients and the public
- Raise awareness through discussion of questions underlying PPI throughout the research cycle
- Offer opportunities to build, share and enhance skills in this area through small group work
- Showcase local practice examples through presentations and exhibits
- Foster networks and links amongst attendees

A theme running through the day's events will be to learn from delegates and focus on the impact of PPI and what counts as meaningful involvement for patients, the public and researchers.

How will this work on the day?

The format of this event will be mainly debate, discussion and learning in smaller groups, either at café style tables, in workshops, or by talking to policy and practice partners, patients and researchers about their work.

The programme (outline overleaf) will include national and local perspectives and updates on PPI, and some brief examples of PPI at all stages of the research cycle. We hope to stimulate creative thinking, and encourage participants to reflect on the implications for their work.

Who should attend?

- Members of the public, with experience of, or engaged in health research or PPI activities

- Organisers and leaders of patient and public groups, and PPI networks and programmes
- Staff working in any area of public health including the third sector, Local Authority and NHS
- Academic researchers and students

Outline Programme

09:30	**Registration/Arrival**
10:00	**Chair's Introduction** (Dr Simon Forrest, Head of School, School of Medicine, Pharmacy and Health, Durham University)
10:15	**Icebreaker discussions** Facilitated question led discussion of the challenges to PPI and making it work. On the day a discussant will reflect on what has been said whilst listening to the table discussions. Later feedback will be written up from each table for the event report
11:00	**Refreshment Break**
11:15 12:00	**Morning Plenary** Cllr Nick Forbes, Leader, Newcastle City Council *(30 minutes + 15 minutes Q/A)* Series of 5 minute reports on PPI input to the stages of the research cycle: • Reaching the target audience – who? and how? • Identifying the research question • Making a grant application • Data collection and analysis • Dissemination and impact
12:30	**Interactive Lunch** Tables/Exhibitions
13:15	**Parallel Workshops – Session 1** (45 minutes) Final titles to confirm – this listing describes the workshop content: • Dave Green/Susan Hrisos – experience of public involvement in research to develop a patient safety system • Johanna Smith and Lindsay Pennington – work in the field of speech and language therapy for children with cerebral palsy • Janice McLaughlin – work with young people • Dan Duhrin – INVOLVE North East workshop Reaching the target audience – who? and how? • Silvia Scalabrini – organisational approaches to PPI
14:00	**Parallel Workshops – Session 2** (45 minutes) An opportunity to attend a second workshop from the above choice
14:45	**Refreshment Break**
15:00	**Afternoon Plenary** Simon Denegri, Chair of INVOLVE and National Director for Public Participation and Engagement in Research, NIHR *(30 minutes + 15 minutes Q/A)*
15:45	**Panel Questions/debate**
16:15	**Chair's closing remarks**

About the Venue
The Beacon, Westgate Rd, Newcastle, NE4 9PQ, is a modern fully accessible building. The QRM is being held in the top floor conference suite. If you wish to find out more, please visit www.thebeaconnewcastle.co.uk

Travelling
The venue has a 65 space car park, and, if full, there is street parking in neighbouring residential roads without restrictions. The Beacon is well served by buses, numbers 38, 10 and 11 leaving from the Central Station and 39 and 40 from Eldon Square. Passengers should alight at the bus stop opposite the General Hospital and continue a short distance up Westgate Rd, where the Beacon is on the left. Please note that The Beacon cannot be reached by Metro. For detailed directions by road from the Central Station or the A1, please follow this link:
http://www.thebeaconnewcastle.co.uk/wp-content/uploads/2011/05/Directions-to-The-Beacon.pdf

July 30th 2014

INVOLVE

NHS
National Institute for
Health Research

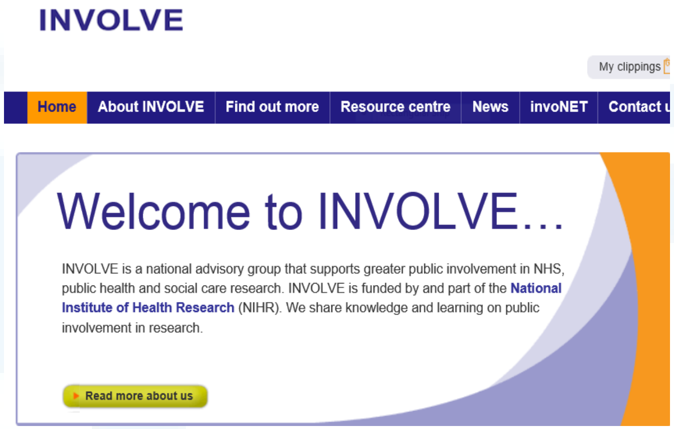
Beyond tokenism: public involvement with impact

Simon Denegri, NIHR National Director for Patients and the Public and Chair, INVOLVE (UK)

fuse, Newcastle, 16th October 2014

UK leadership in public involvement in research

- International leader in public involvement
- Core principle of National Institute for Health Research (NIHR)
- Clear expectation set with research community
- £ Investment and practical support
- Partnership approach

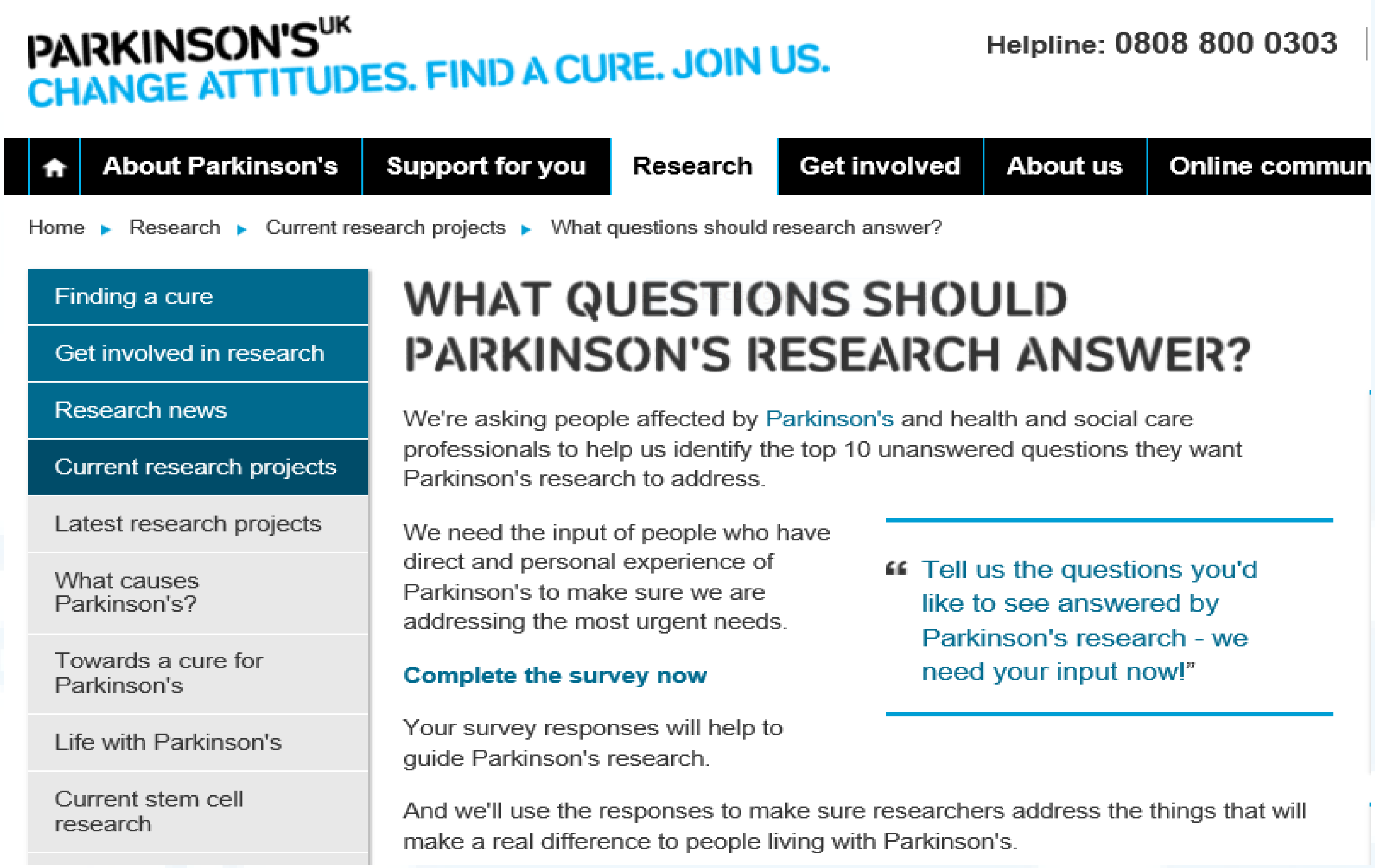


Welcome to INVOLVE…

INVOLVE is a national advisory group that supports greater public involvement in NHS, public health and social care research. INVOLVE is funded by and part of the **National Institute of Health Research** (NIHR). We share knowledge and learning on public involvement in research.

www.invo.org.uk

Making research relevant



WHAT QUESTIONS SHOULD PARKINSON'S RESEARCH ANSWER?

We're asking people affected by Parkinson's and health and social care professionals to help us identify the top 10 unanswered questions they want Parkinson's research to address.

We need the input of people who have direct and personal experience of Parkinson's to make sure we are addressing the most urgent needs.

Complete the survey now

Your survey responses will help to guide Parkinson's research.

> “Tell us the questions you'd like to see answered by Parkinson's research - we need your input now!”

And we'll use the responses to make sure researchers address the things that will make a real difference to people living with Parkinson's.

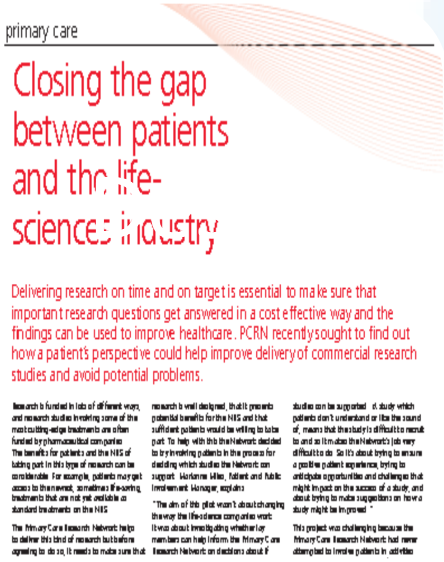
http://www.netscc.ac.uk/news/item/08042013.asp

Increasing effectiveness and efficiency

‘The aim of patient and public involvement
is to improve the quality, feasibility and translational value of research...[This] is the first time
we can see that patient involvement is linked to higher likelihood of reaching recruitment target – and as a result, study success.’

Professor Til Wykes, Director, MHRN
‘Patient involvement in research boosts success,’
The Guardian, 16/09/13

Paper reference: Ennis, L. et al. ‘Impact of patient involvement in mental health research: longitudinal study’ *British Journal of Psychiatry* (Sept 2013) [doi: 10.1192/bjp.bp.112.119818](https://doi.org/10.1192/bjp.bp.112.119818)

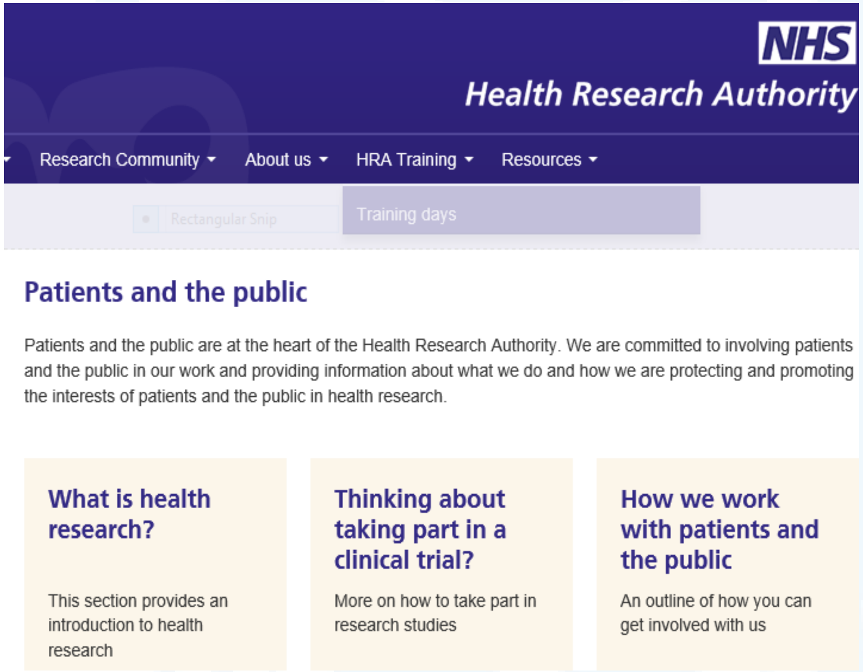


primary care

Closing the gap between patients and the life-sciences industry

Delivering research on time and on target is essential to make sure that important research questions get answered in a cost effective way and the findings can be used to improve healthcare. PCRN recently sought to find out how a patient's perspective could help improve delivery of commercial research studies and avoid potential problems.

Ensuring public confidence



Patients and the public

Patients and the public are at the heart of the Health Research Authority. We are committed to involving patients and the public in our work and providing information about what we do and how we are protecting and promoting the interests of patients and the public in health research.

What is health research?

This section provides an introduction to health research

Thinking about taking part in a clinical trial?

More on how to take part in research studies

How we work with patients and the public

An outline of how you can get involved with us

- 77% of people said that knowing a Research Ethics Committee had reviewed a study would increase their confidence in it.
- 44% of respondents thought that involving patients....would increase their confidence in the study.

Ipsos MORI study for HRA: 2013
http://www.hra.nhs.uk/news/2013/11/22/patient-involvement-increases-public-confidence-health-research/#sthash.x3fCMNWj.dpuf

Building research communities: young people in research

medicines for children

medicines for children

Young people help researchers to “get real”

Clinical research is evolving. Increasingly, there is pressure on the research community to ensure that treatments are relevant and effective in daily life. This is driving more researchers to seek the input of service users in the development of their work, which is leading to a transformation of the cultural and regulatory environment for children's research.

▲The Young Persons' Advisory Group is growing in size and influence

The NIHR Medicines for Children Research Network (MCRN) has been at the forefront of patient and public involvement in research for some time. In 2006, the Network started its first Young Persons' Advisory Group in Liverpool. Since then, four more groups have been established in London, Nottingham, Birmingham and Bristol.

The initial remit of these groups was straight forward: to engage young people with research and to work in partnership with, and offer support to, researchers. Jenny Newman, NIHR Medicines for Children Research Network Consumer Liaison Manager, explains how this role has evolved:

“We set up the group to provide a forum for young people to learn about, and comment on, various aspects of the research cycle from the identification of research questions to the dissemination of research findings. We are now working with national governing bodies and helping to remodel the guidance they provide to researchers to help them design and deliver ethically robust research for children, as well as support researchers in the design and deliverability of their studies.”

> “Young people... want to know what the study will mean to them.”

Parents are able to consent for children to take part in clinical research if they are under 16 years of age. But researchers have to gain the assent of children too, which is why they receive guidance on how to produce materials to help young people understand a study.

The National Research Ethics Service (NRES) is responsible for producing this guidance. When they decided to review their materials, NRES approached the Medicine for Children Research Network about working with the Young Persons' Advisory Group:

“We conduct training for researchers in the area of ethics guidance and over the last five years the MCRN's Young Persons' Advisory Group has become an important part of our meetings”, explains Dr Hugh Davies, consultant paediatrician and Research Ethics Advisor at NRES. “As a result, we wanted their input in our guidance review, which has led to a major statement of how we should approach children.”

Group members felt that NRES guidance was producing study materials that failed to meet their needs. Holly Lamden is 18 years old, and a member of the Liverpool Young Persons' Advisory Group:

“A lot of the materials we see are highly formulaic. They are clearly designed to tick legal and governmental boxes, but they

workshop with the Young Persons' Advisory Group to determine whether the research question she was proposing was valid. She feels that, in an increasingly competitive environment, this input can prove vital:

“It's powerful that the people experiencing a diagnostic device have helped to shape it. Their involvement makes a study more competitive because it provides us with perspectives that we can't find anywhere else. It makes the product more likely to succeed and helps us avoid the development of expensive products that children do not want to use.”

Dr Davies agrees that involving children at the beginning of the research process is crucial:

“The research community is concentrating on studies that are relevant and shaping the right question is key to this. The opportunity for genuine influence is limited, which is why it needs to be embedded in the early stages of research development.”

With the paediatric research community increasingly focusing on the real-world relevance of research, the influence and impact of the Young Persons' Advisory Group is set to grow. In September this year it is holding its first national event for the life-sciences industry in which a wider range of organisations will gain an insight into how young people and families can have a positive impact on the development of clinical research.

www.mcrn.org.uk

Watch a Young Persons' Advisory Group member's video diary by visiting: **www.crncc.nihr.ac.uk/researchpeople**

> esearchers need to make a
> tinction between child and
> t studies. Paediatric studies
> need to stand alone.”

6 Young people help researchers “get real”

Young people help researchers “get real” 7

January 2013 | Issue 2

NHS
National Institute for Health Research

Faculty world

the magazine for NIHR people

Patient and public involvement

The "hidden heroes" of diabetes research

The School for Social Care Research

Attracting, developing and retaining the best people in research

NHS
National Institute for
Health Research

Future strategy development: evolution and revolution

Theme 1: Overall evaluation of progress to date

- **Progress** has been made but not consistently across NIHR
- Research is becoming more **relevant** to patients and carers
- Greater **potential** for implementation of research evidence
- Evidence of **transformative** nature of public involvement personally and professionally

Theme 2: What stops public involvement?

- **Attitudes** - scepticism, mistrust, lack of awareness, communication and curiosity
- **Resources** – time, money, infrastructure to meet increased demand, inconsistent reward and reimbursement policies, procedures and practices across NIHR, NHS, Higher Education and voluntary sector
- **Training and support** – inconsistent opportunities
- **Confusing and inconsistent** expectations from different parts of NIHR combined with variable performance and limited evidence of effective practice and impact
- **Leadership -** more leaders to promote and practice public involvement

Theme 3: Doing public involvement differently

- **Practice** - Increase critical practice – more publication on ‘how’, introduce standards
- **Promotion**- Better promotion of effective involvement, more outreach
- **Learn** from other sectors and disciplines
- Only fund studies and programmes where there is confidence about the **standard** of public involvement
- **Inclusive** – more reflective of wider society

Theme 4: How do we do it? The future design and delivery of public involvement in NIHR

- **Coordinate and collaborate** – better strategic development
- **Better models** of collaboration between lay people and researchers
- **Strategic and systematic** approach to the collection of evidence across NIHR

Theme 5: Where should we be with public involvement in NIHR in ten years?

- Public involvement is **normal** and accepted practice
- **Enhanced evidence** base with better consensus on value of public involvement
- **Agreed methods** and indicators of impact
- Greater **public awareness** of research and NIHR
- **Global leadership** in scholarship and the study of public involvement in research

Breaking Boundaries Review

What should public involvement look like in 10 years?

Some clear messages from the community:

- Public involvement is **normal** and accepted practice
- **Enhanced evidence** base with better consensus on value of public involvement
- **Definitions** of quality in public involvement
- **Agreed methods** and indicators of impact
- Greater **public awareness** of research and NIHR
- **Global leadership** in scholarship and the study of public involvement in research

‘We mean business’

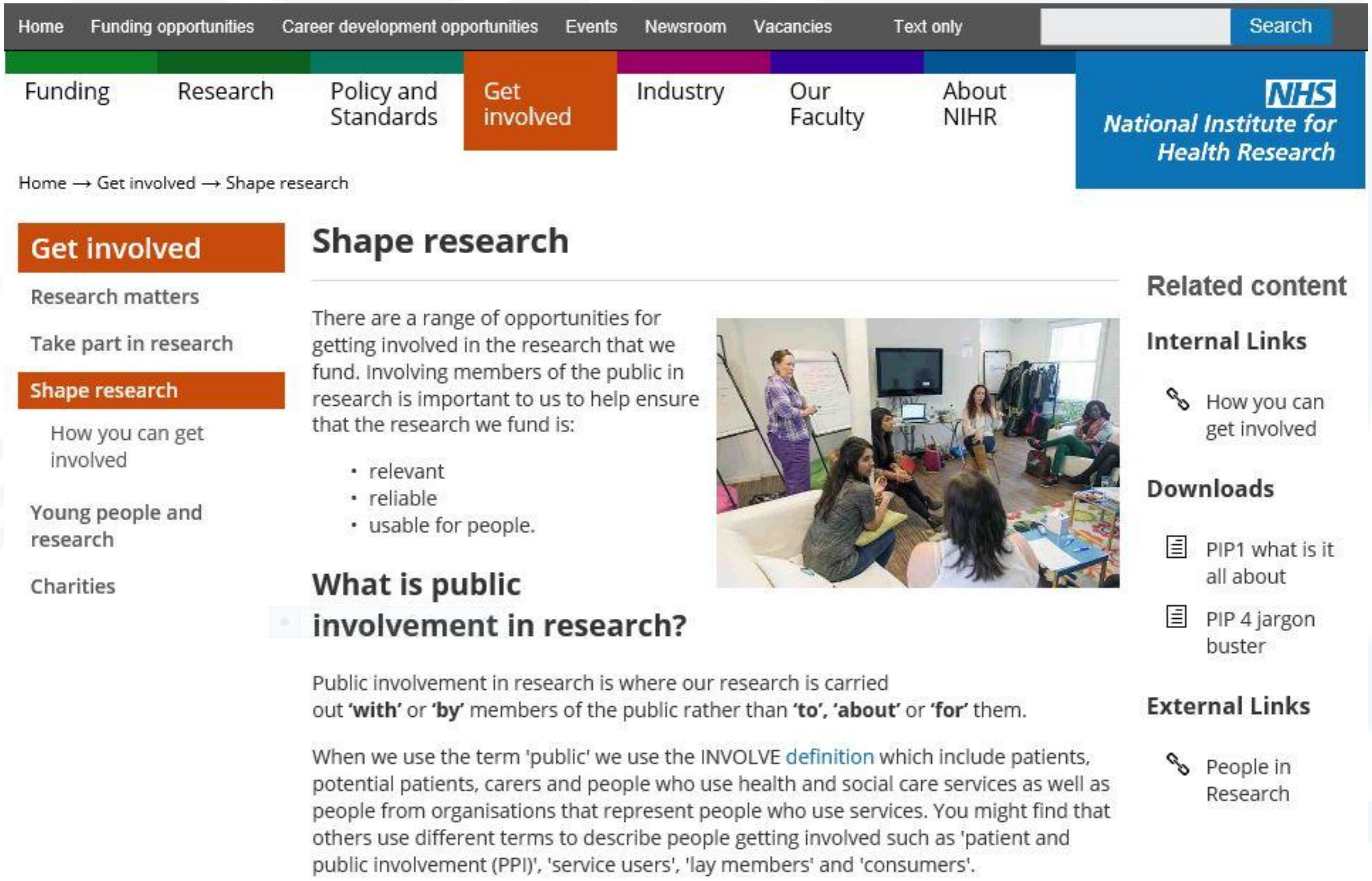
- Strategic direction for the next 10 years setting out:
  - ✓What happens now? 1-2 years

    Measures to increase efficiency and effectiveness…..
  - ✓What happens next? 3-5 years

    Mechanisms and key questions, incentives…..
  - ✓What happens in the future? 5-10 years

    Big picture, blue skies…….

A more user-driven health research system



Shape research

There are a range of opportunities for getting involved in the research that we fund. Involving members of the public in research is important to us to help ensure that the research we fund is:

- relevant
- reliable
- usable for people.

What is public involvement in research?

Public involvement in research is where our research is carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them.

When we use the term 'public' we use the INVOLVE definition which include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. You might find that others use different terms to describe people getting involved such as 'patient and public involvement (PPI)', 'service users', 'lay members' and 'consumers'.

‘We mean business’

- Thematic areas for recommendations:
    - ✓Empowering individuals
    - ✓Definition, strategy and co-ordination
    - ✓Community
    - ✓Design, organisation and delivery
    - ✓Impact and success

What will it mean to be a patient or member of public in research in 2025?

'Invitation only' or co-production of knowledge?

Cometh the hour, cometh the patient

'We stand on the cusp of a revolution in the role that patients – and also communities – will play in their own health and care. Harnessing what I've called this renewable energy is potentially the make-it or break-it difference between the NHS being sustainable – or not.'

Simon Stevens, NHS CEO, NHS Confederation Annual Conference, June 2014

NHS
National Institute for
Health Research

Working with the NHS to improve participation and engagement

“Some people sit in a bath of baked beans or run a marathon. For me, I just thought ‘if not me then who?’ “It’s nice to be part of it and it gives you a way to help.”

Sheridan Edward

Opera singer, Ebola vaccine clinical trial volunteer on standby!

From willing to active patients

Public appetite

- 82 per cent of people believe it is important for the NHS to offer opportunities to take part in healthcare research.
- Less than 7% said they would never take part in a clinical research study.

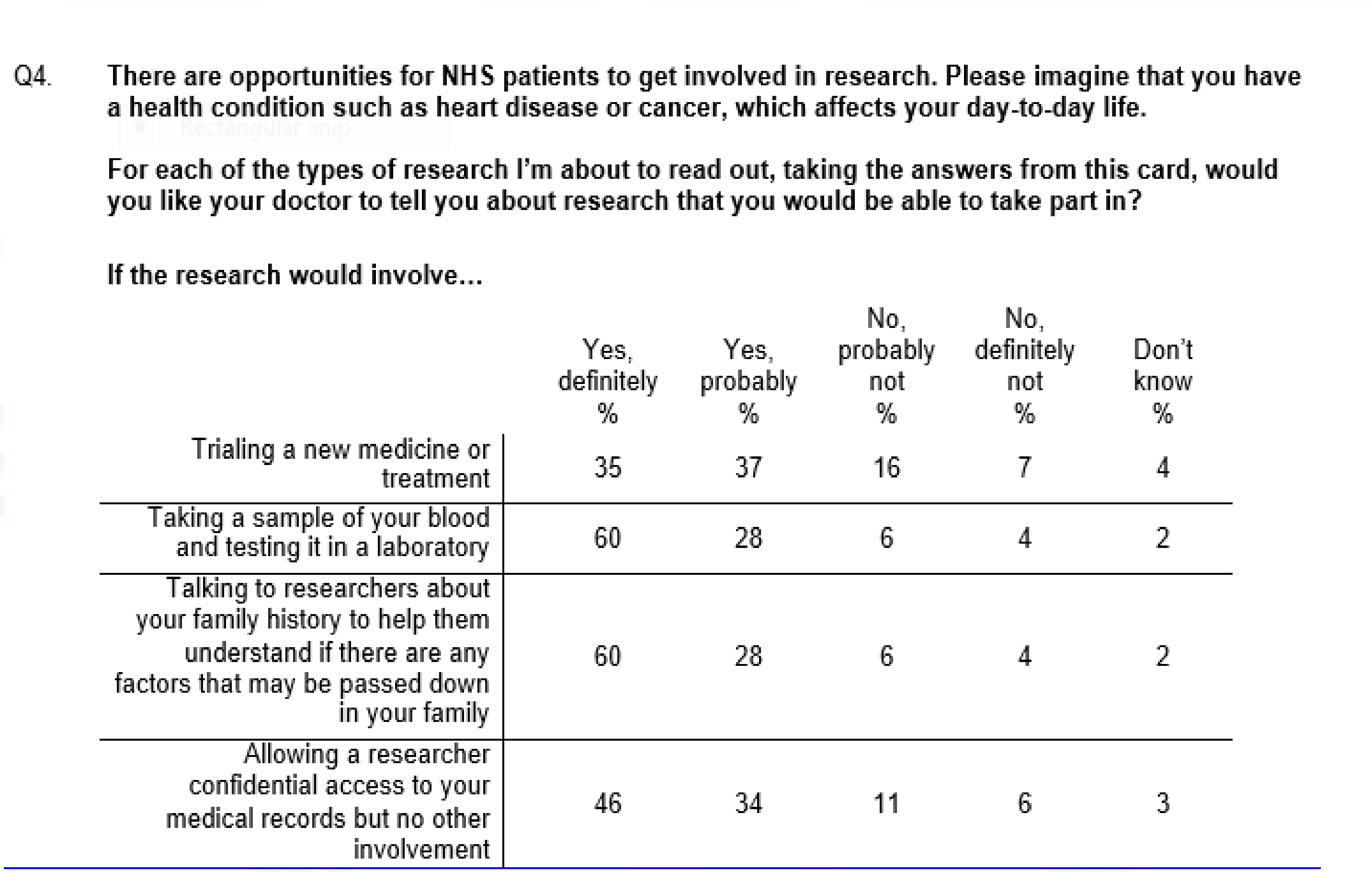
  NIHR Clinical Research Networks Survey May 2012
- Over 70% of patients look for information about clinical trials

  ecancer 5 235 2011 'Information needs of cancer patients'

Patient experience

- National Cancer Patient Experience Survey 2012 and 2013
  - 1 in 3 patients had a discussion about research with a health professional
- Discussion much less likely if happening at all for patients with other conditions (i.e. 1 in 5 for type 1 diabetes)
- 91% of Trusts do not provide information to support patient choice in research: NIHR CRN CC Mystery Shopper 2013

From willing to active patients



Q4. **There are opportunities for NHS patients to get involved in research. Please imagine that you have a health condition such as heart disease or cancer, which affects your day-to-day life.**

For each of the types of research I'm about to read out, taking the answers from this card, would you like your doctor to tell you about research that you would be able to take part in?

If the research would involve...

	Yes, definitely %	Yes, probably %	No, probably not %	No, definitely not %	Don't know %
Trialing a new medicine or treatment	35	37	16	7	4
Taking a sample of your blood and testing it in a laboratory	60	28	6	4	2
Talking to researchers about your family history to help them understand if there are any factors that may be passed down in your family	60	28	6	4	2
Allowing a researcher confidential access to your medical records but no other involvement	46	34	11	6	3

IPSOS MORI Poll for Association of Medical Research Charities, 2011

‘Promoting a research active nation’

NIHR Strategic Plan for Participation and Engagement launched on 20 May 2014

- Better outcomes for all in health and care
- People choosing to take part in research
- People defining research of the highest quality
- People understanding the evidence on which their care is based
- Improving people’s experience in research

From willing to active patients

- ✓Asking about research
- ✓Choosing to take part in research
- ✓Knowing their contribution has made a difference
- ✓Shaping the way in which research is designed and delivered
- ✓Leading change at local and national level to make research happen
- ✓Reporting on and sharing their experiences with commissioners and providers

‘Promoting a research active nation’

- Supporting choice, promoting participation

  UK Clinical Trials Gateway (UKCTG), OK to Ask, accessible information, removing barriers to recruitment…

- Learning from patient experience

  Measuring access to research, ‘respect and dignity’ agenda, a participant’s charter….

- Supporting citizens to champion and lead research

  Research ambassadors,

  local partnerships, research active

  communities……

Ambassadors and champions

research changed my life

OK TO ask about clinical research

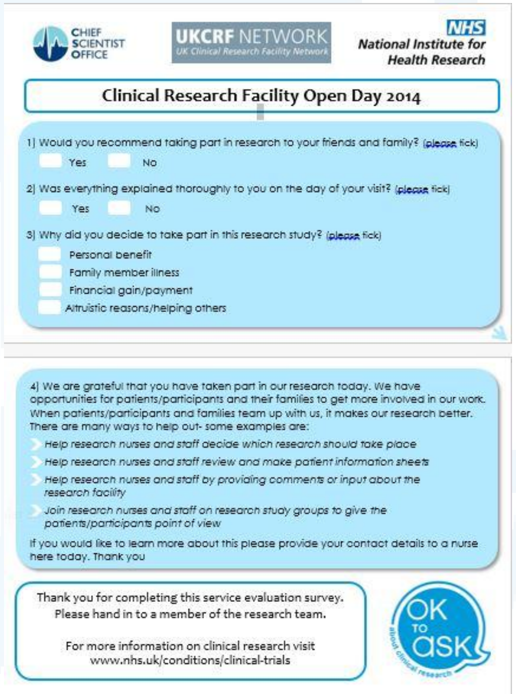
‘OK to Ask’ campaign: International Clinical Trials Day 2014

- Encouraging patients and carers to ask their clinician about clinical research (and log response/suggestions)
- Encouraging clinicians to consider their response if a patient does ask: how to channel interest

Improving the patient experience

Improving patient experience:

- Removing barriers
- Information and consent
- Quality of care
- Relationship with professionals
- When the trial is over – results and acknowledgement?



CHIEF SCIENTIST OFFICE

UKCRF NETWORK
UK Clinical Research Facility Network

NHS
National Institute for Health Research

Clinical Research Facility Open Day 2014

1] Would you recommend taking part in research to your friends and family? (please tick)

☐ Yes ☐ No

2] Was everything explained thoroughly to you on the day of your visit? (please tick)

☐ Yes ☐ No

3] Why did you decide to take part in this research study? (please tick)

☐ Personal benefit
☐ Family member illness
☐ Financial gain/payment
☐ Altruistic reasons/helping others

4] We are grateful that you have taken part in our research today. We have opportunities for patients/participants and their families to get more involved in our work. When patients/participants and families team up with us, it makes our research better. There are many ways to help out- some examples are:

- *Help research nurses and staff decide which research should take place*
- *Help research nurses and staff review and make patient information sheets*
- *Help research nurses and staff by providing comments or input about the research facility*
- *Join research nurses and staff on research study groups to give the patients/participants point of view*

If you would like to learn more about this please provide your contact details to a nurse here today. Thank you

Thank you for completing this service evaluation survey.
Please hand in to a member of the research team.

For more information on clinical research visit
www.nhs.uk/conditions/clinical-trials

“I have always taken the view that public involvement in research should be the rule not the exception.”

Professor Dame Sally Davies
Chief Medical Officer (CMO)

INVOLVE

NHS
National Institute for
Health Research

Questions

Simon.Denegri@nihr.ac.uk
Twitter: @SDenegri
Blog: http://simondenegri.com/

OK TO ASK about clinical research

NHS
National Institute for
Health Research
UKCTG

Patient and Public Involvement in Research

Helpful Resources list

INVOLVE

INVOLVE is funded by the NIHR to support public involvement in NHS, public health and social health care research.
http://www.invo.org.uk

INVOLVE publications list 2014

The INVOLVE publications list highlights a selection of the current guidance and evidence publications.
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

INVOLVE Useful links

The INVOLVE links include details of research websites and organisations that might be helpful for researchers and members of the public who have an interest in active public involvement in research.
http://www.invo.org.uk/resource-centre/useful-information/links

Public Involvement Impact Assessment Framework (PiiAF)

PiiAF has been produced to help researchers assess the impacts of involving members of the public in their research in diverse fields from health care to local history.
http://piiaf.org.uk

Research Design Service

The Research Design Service North East is funded by the NIHR to provide support to those preparing grant applications for submission to national, peer-reviewed funding competitions for applied health or social care research.
http://rds-ne.nihr.ac.uk/about/contact-us

VOICENorth

VOICE (Valuing our Mental Capital and Experience) North is a lively and creative organization, based at Newcastle University since 2009. Voice North has invested in creating a flourishing community of research active citizens, with partnerships between members of the public and patients working with academics, policy makers and businesses to co-create and translate research evidence and supporting innovation.

Email: Voicenorth@ncl.ac.uk
Website: http://www.ncl.ac.uk/ageing/innovation/engagement/voicenorth

Engagement Team in the Faculty of Medical Sciences at Newcastle University

Contact Details

Helen Atkinson
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Email: FMS.Engagement@newcastle.ac.uk
Contact: 0191 208 1287/1288
Twitter: @EngageFMS

Centre for Social Justice and Community Action

The Centre for Social Justice and Community Action is a research centre at Durham University, made up of academic researchers from a number of departments and disciplines and community partners. Our aim is to promote and develop research, teaching, public/community engagement and staff development (both within and outside the university) around the broad theme of social justice in local and international settings, with a specific focus on participatory action research.
www.durham.ac.uk/beacon/socialjustice

National Co-ordinating Centre for Public Engagement

The National Co-ordinating Centre for Public Engagement's works to help support universities to improve, value and increase the quantity and quality of their public engagement and embed it into their core practice.
Centre for Social Justice and Community Action, Durham University and the National Co-ordinating Centre for Public Engagement (2012) **Community-based participatory research. A guide to ethical principles and practice** available from www.publicengagement.ac.uk

NHS Midlands and East

NHS Midlands and East (2012). Good engagement practice for the NHS: Involving patients, carers, communities and staff to improve health outcomes.
http://www.haref.org.uk/documents/Good%20engagement%20practice%20for%20the%20NHS[1].pdf

Potentially useful references:

Ennis, L. & Wykes, T. (2013) Impact of patient involvement in mental health research: longitudinal study. The British Journal of Psychiatry, EPub ahead of print, doi: 10.1192/bjp.bp.112.119818
Brett J, Staniszewska S, Mockford C (2010) The PIRICOM Study. A Systematic Review of the

Conceptualisation, Measurement, Impact and Outcomes of Patient and Public Involvement in Health and Social Care Research. London: United Kingdom Clinical Research Collaboration.

Staley K (2009) Exploring Impact: Public involvement in NHS, public health and social care research. Eastleigh: INVOLVE.

Other tools for enhancing capture and reporting of PPI in research

Staniszewska S, Brett J, Mockford C, Barber R (2011) The GRIPP checklist: strengthening the quality of patient and public involvement reporting in research. International Journal of Technology Assessment in Health Care 27:4.

Morrow, E., et al. 2010. A model and measure for quality service user involvement in health research. International Journal of Consumer Studies. 34. Pp.532-539.

Quarterly Research Meeting – Summary Report

Beyond Tokenism: PPI with impact
Enriching patient and public involvement in public health research
Thursday 16th October 2014

The Beacon Centre, Westgate rd; Newcastle Upon Tyne

Introduction

This report summarises the keynote speaker's presentations, and the concluding panel discussion session at the October Quarterly Research Meeting held on the topic of "Beyond Tokenism: PPI with impact, Enriching patient and public involvement in public health research" The QRM was organised a grouping of Fuse, Newcastle University (Institute for Social Renewal) and Involve North East. This summary report is to be read in conjunction with the slide sets kindly provided by our speakers, also on the Fuse website. The slides are cross-referenced in the summary account, below. In addition you will also find the abstracts for the parallel workshops posted on the website, alongside this summary report.

PLENARY SPEAKERS

Towards a new citizenship for health: Nick Forbes, Leader, Newcastle City Council and CEO, Involve North East

Nick Forbes began his presentation by outlining the content of his talk (as listed on Slide 2) and referring to his experiences within a "Common Purpose" group, which had given him an insight into considering health issues in a variety of environments. He returned to the institution of the NHS in 1948 by showing the cover of the original public information leaflet delivered across the UK (Slide 3), indicating that at that stage there was no choice - people either used the NHS or paid to be treated privately. Over succeeding decades there had been substantial progress in preventative vaccination and screening programmes (as listed on Slide 4) and also new medical advances in treatment (also on Slide 4). Technological improvements based on doing ever more was the order of the day, which raised longer term questions about if this cumulative approach could be financially viable.

Choice for the public first emerged in the 1990s in the form of helplines (like NHS Direct) NHS Choices and walk-in centres, (see Slide 5). These developments broke the single point of contact being through the GP and the GP alone. The speaker then moved on to changes in local government alongside the changes that he had described in the NHS. In 1972 the Local Government Act created standardised functions across England (see map of local authorities in Slide 6) and the services local government developed into providing could be categorised under the headings of 'place' and 'people'; in the latter case providing a personal service of some sort and this has been augmented by the addition of public health since 2013 (see Slides 7 and 8). The list of public health services that local government is now responsible for (see Slide 8) is still medically dominated and concentrates on treatment and prevention, rather than being more fundamentally transformative. Traditionally the

NHS, when it has considered involvement has equated this with service design and delivery. For the local authority, this is different because of local elections, although turnout nationally was 36% (see Slide 9) and in Newcastle that figure was lower at 33%. Consequently involvement can't just be about democracy, given these low participation figures.

Nick Forbes then moved on to talk about personalisation (also set out on Slide 9). He described this concept which involves, following assessment, the person being given a budget to spend on their assessed needs. However the scope for implementing this has been affected by austerity measures. Slide 10 depicts spending changes nationally between 2010-11 and 2014-15, and attention was drawn to two elements of the bar chart. These were changes in NHS England (almost unchanged at -0.2%) and local government, where there had been a reduction of -27.3%. This was an unprecedented level of cuts not seen since 1981-82. Slide 11 compared two maps of England, one depicting cumulative cuts to Councils (where darker areas have had greater cuts) and another showing the Index of Multiple Deprivation where more deprived areas were also in a darker shade. These two maps placed alongside each other show a strong association between the greater cuts and greater deprivation, which was inducing a stronger sense of crisis in the most affected areas. It was stated that there was a similar picture for the NHS but less pronounced.

The issues described meet within the responsibilities of the Health & Wellbeing Board. Slide 12 sets out the main parameters for the make-up and functions of the Boards. In Newcastle the membership has been extended to include additional stakeholders. A contrast was drawn between the expectation that the Boards would influence commissioning plans and produce Join Strategic Needs Assessments, but without dedicated resources and powers, conducting business entirely on the basis of good will. Nonetheless Health & Wellbeing Boards are seen as 'the pinnacle of leadership' but are not necessarily the people who can deliver population health as that's a broad responsibility. The work of the Board was described as being analogous to getting a tortoise to dance (see Slide 13). The process of developing a wellbeing for life strategy in Newcastle was described (see Slides 14 and 15). Slides 15 and 19 sum up the 4 main priorities (reduced from a historical 43):

- Establishing the working city – jobs of good quality, a healthy economy
- Decent neighbourhoods – healthy places and communities
- Tackling inequalities – on the basis that fairer societies are healthier – through service distribution
- A cooperative Council fit for purpose

A quote from Saul Alinsky setting out his philosophy of participation was shown (Slide 16) followed by a short video clip featuring Chris Brink (embedded in Slide 17). Slide 18 is an extract from the Lancet Commission (2012) document on shaping cities for health, that brings out the importance of participation by stakeholders and the use of a wide range of knowledge and sources, and was used to indicate that this thinking had underpinned identifying the four priorities of the wellbeing for life strategy.

Slide 20 presents a series of conclusions. The starting point is that traditionally public services define need and allocate resources to meet the need, but this approach is unsustainable. Consequently a new approach is needed based on involvement and cooperation to tackle issues together, taking into account changes in technology which rely much more on the individual taking responsibility (See Slide 21 which compares a traditional ECG in a hospital department and wearable technology.) The final two slides present a series of questions for research/researchers and quotations from the Wellbeing for Life strategy which illustrate how individuals perceive and define health.   Questions following the presentation included the issues of minority representation and how the NHS measures and undertakes involvement.

INVOLVE: Beyond Tokenism: public involvement with impact: Simon Denegri, NIHR National Director for Patients and the Public and Chair INVOLVE (UK)

Simon Denegri started his presentation by setting the scene for health research in the UK. He compared this with a three-legged stool comprising of three main sources of funding, the government, (through NIHR – National Institute for Health Research, and MRC – the Medical Research Council for example), industry (such as the pharmaceutical industry) and charities, which make the highest contribution globally. He made the point that these sources of funding need to be kept in balance. Public involvement under the banner of INVOLVE is about the active involvement of the public in the whole research cycle, of which engagement and dissemination is an offshoot. The UK is an international leader in public involvement (see Slide 2). Leading on from this, a core principle of NIHR is a clear expectation of public involvement in research (see Slides 3-6).

Simon Denegri gave some examples of priority setting including significant numbers of people. He indicated that there was evidence of increasing the effectiveness and efficiency of the execution of projects through public involvement – in general terms the greater the public involvement the better the project set up, feasibility and participant recruitment. Public confidence in the research is also improved through public involvement, (for details see Slide 5). The role of young people in research communities was highlighted (see Slide 6). Simon Denegri suggested that, in his experience, researchers were anxious about public and patient involvement and benefitted from learning activities in this field.   The next section of the presentation dealt with the results of a NIHR national survey categorised under a series of five themes (covered in Slides 9-13).

Theme 1 considers the overall picture of progress to date.   This showed that progress had been made but not consistently across the NIHR, research was becoming more relevant to patients and carers, there was greater potential for implementation of research evidence and evidence of the transformative nature of public involvement personally and professionally. Theme 2 (slide 10) considers what inhibits patient involvement under the headings of attitudes, resources, training and support, expectations and leadership. Theme 3 (slide 11) reflects some topic areas for improving public involvement. An additional comment was made that the nature of public involvement needs to be more ethnically diverse. Theme 4 (slide 12) considers the future design and delivery of public involvement in NIHR, setting out the main headings for this and leads on to Theme 5 (slide 13) which presents a vision of where the NIHR should be with public involvement in ten years time. This is developed in more detail in Slides 14 and 15. Simon Denegri made a strong stance for a more user-driven health research system (slide 17) taking a cue from the more user driven health services – in short research lags behind provision of services. He made the point that public involvement has tended to be ‘by invitation only’ due to the way institutions are set up. It is important to make the transition from this position to true co-production of knowledge.

A slide was shown with a quotation from Simon Stevens (NHS CEO, delivered to a national conference in June 2014) which underlined the role of patients and communities in their own care, and using a concept which he had called “renewable energy” to describe their role. Simon went on to make the point that not enough people are invited to take part in research and drew attention to the paradox that in the UK the general population are very pro-medical research but tend not to be asked to participate, apart from cases of rare diseases where a particular committed community forms the recruitment pool. Slides 22-25 explore how patients could be included more actively leading up to Slide 25 headed “Promoting a research active nation” which sets out the headline objectives of the NIHR strategic plan for participation and engagement launched in May 2014. Slides 26-29 describe in more detail how patients can be more positively included as active participants and their experience of being part of a project improved and recognised. Simon Denegri referred to an example of an embedded patient advisor for trials based within the R&D team in Maidstone Hospital, Kent as a particularly good illustration of patient inclusion. In particular citizens tend not to be thanked for their involvement in research and it’s difficult for the public to learn the results of trials they have taken part in. Consequently the EU have passed legislation to improve access. The final substantive slide (Slide 31) includes a quotation from Professor Dame Sally Davies (Chief Medical Officer) to sum up, “I have always taken the view that public involvement in research should be the rule not the exception”.

Slide 32 (final slide) provides Simon Denegri’s contact details. Questions following the presentation led to discussion about applying for funding to assist with patient and public involvement and how to increase the profile of involvement in public health. One suggestion was to make involvement count in professional portfolios.

PANEL DISCUSSION

The concluding session of the day was a panel discussion. Questions were gathered from the audience during the course of the day and five selected for the panel. The content of all the questions posed can be found in a separate document on the website alongside this report. Panel members were: Val Bryant (a patient with extensive experience of research involvement), Nick Forbes and Simon Denegri (plenary speakers, see above), Sue Lewis (a qualitative research specialist with the Research Design Service based at Durham University) and Lynne Corner (Deputy Director, Engagement, Newcastle University Institute for Ageing). The session was chaired by Mandy Cheetham (PDRA, translational research programme, Fuse from Teesside University).

Questions selected for the day were:

1. Can and how can, the public knock on the Universities’ doors?
2. How do we involve “difficult to reach” populations? Not just the ‘usual suspects’ but men, younger people etc (the silent majority)

3. How do we reach the people who are making the decisions about what gets funded?
4. How do we measure the impact of public engagement/involvement?
5. What next after the research project has ended – follow up opportunities for PPI?

Q - Can and how can, the public knock on the Universities' doors?
A – Routes were suggested, (for example via the good offices of Fuse) but limitations were also acknowledged. Suggestions were made for the ways Universities could improve the position by improved websites to encourage engagement and a one-stop shop to help navigate University organisations. It was noted that social involvement doesn't currently count in University rankings and that leaders in public health could pioneer change.

Q - How do we involve "difficult to reach" populations? Not just the 'usual suspects' but men, younger people etc (the silent majority)
A – One panel member stressed the importance of forming longer term relationships and collaborating beyond the life of the project, because the people themselves have long term issues. It was stressed that the VCS (voluntary and community sector) can reach people that others can't, and that understanding is improving of some sectors of the population, for example the different elements of the black and minority ethnic populations. There are also big generational differences which require a different approach. In conclusion the more diverse the approach the better to reach all groups.

Q - How do we reach the people who are making the decisions about what gets funded?
A - One approach suggested was to lobby politicians about science funding. Individual involvement was advocated so that one could have a say. It was stressed that it was important to include PPI costs in funding applications and to raise the issue in reporting of studies.

Although selected to be put to the panel Questions 4 and 5, above, were not used for logistical reasons.

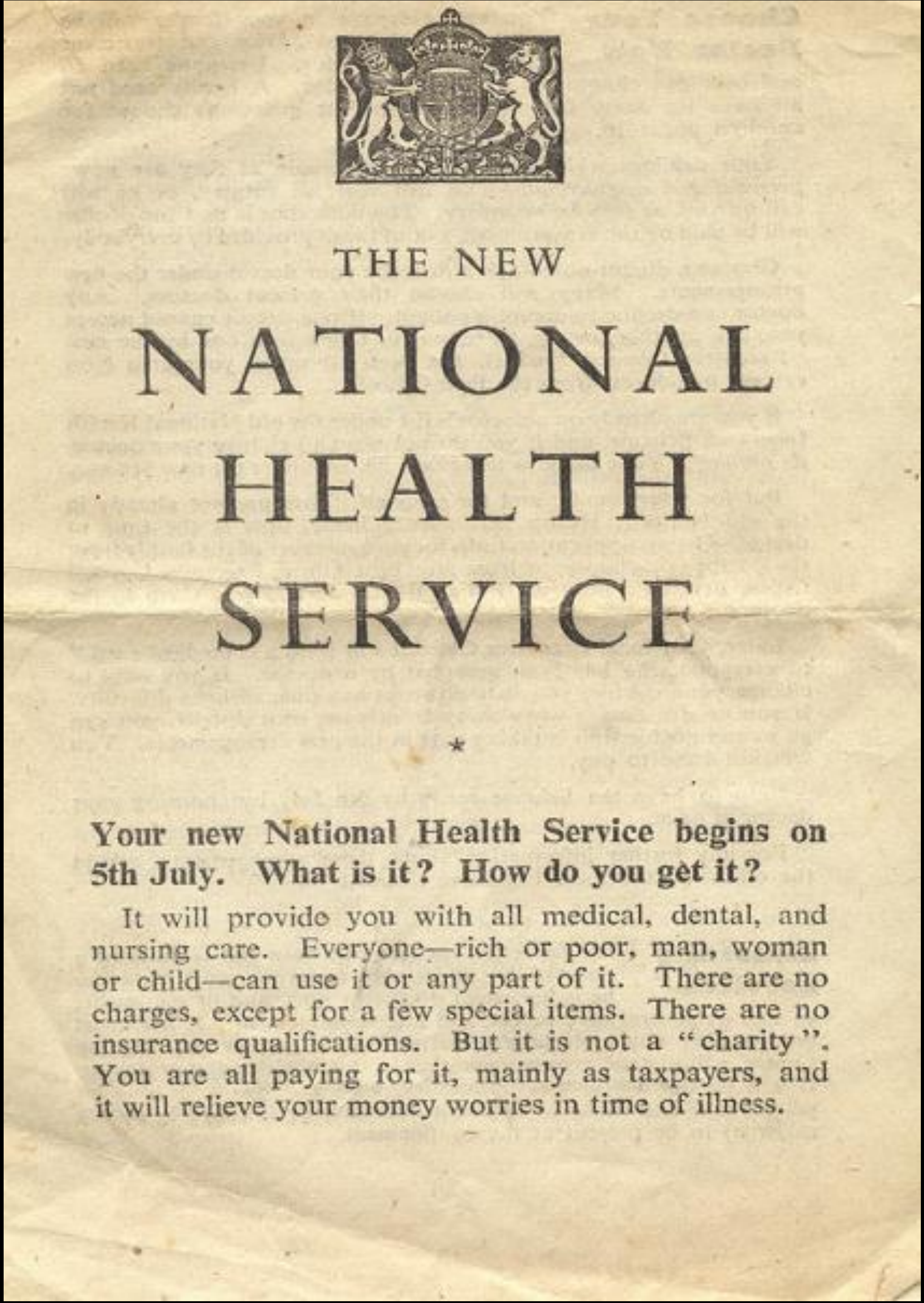
Avril Rhodes
Mandy Cheetham
14th November 2014

Towards a new citizenship for health

Nick Forbes
Leader, Newcastle City Council and
CEO, Involve North East

16th October 2014

- Context and History – different traditions of involving people
- Health and Wellbeing Boards
- Newcastle’s approach in a time of austerity
- Some conclusions and challenges
- What would co-produced health look like?



THE NEW NATIONAL HEALTH SERVICE

*

Your new National Health Service begins on 5th July. What is it? How do you get it?

It will provide you with all medical, dental, and nursing care. Everyone—rich or poor, man, woman or child—can use it or any part of it. There are no charges, except for a few special items. There are no insurance qualifications. But it is not a "charity". You are all paying for it, mainly as taxpayers, and it will relieve your money worries in time of illness.

Health advances

Population health:

- 1959 – Polio and Diphtheria vaccination programmes
- 1961 – Contraceptive pill
- 1986 – “Don’t Die of Ignorance” campaign
- 1988 – breast screening

Medical progress:

- 1960 – Kidney transplants
- 1962 – Hip replacements
- 1968 – Heart transplants
- 1972 – CT scanners
- 1978 – IVF
- 1985 – Liver transplants

NHS Choices

NHS choices Your health, your choices

NHS Direct

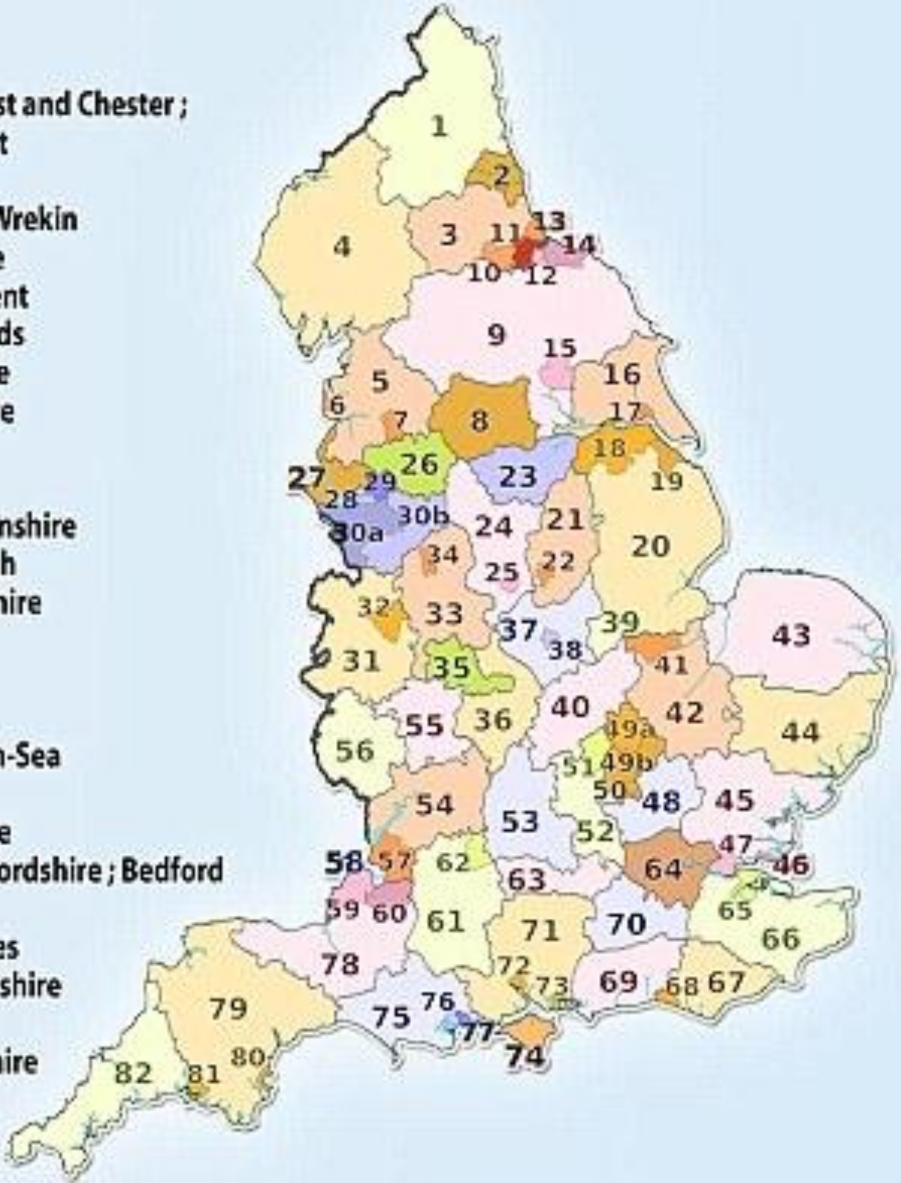
CALL 24 HOURS ON 0845 4647

Welcome to NHS Direct

Your gateway to health information on the Internet

1 Northumberland
2 Tyne and Wear
3 Durham
4 Cumbria
5 Lancashire
6 Blackpool
7 Blackburn with Darwen
8 West Yorkshire
9 North Yorkshire
10 Darlington
11 Stockton-on-Tees
12 Middlesbrough
13 Hartlepool
14 Redcar and Cleveland
15 York
16 East Riding of Yorkshire
17 Kingston upon Hull
18 North Lincolnshire
19 North East Lincolnshire
20 Lincolnshire
21 Nottinghamshire
22 Nottingham
23 South Yorkshire
24 Derbyshire
25 Derby
26 Greater Manchester
27 Merseyside
28 Halton

28 Warrington
29 Cheshire West and Chester ; Cheshire East
30 Shropshire
31 Telford and Wrekin
32 Staffordshire
33 Stoke-on-Trent
34 West Midlands
35 Warwickshire
36 Leicestershire
37 Leicester
38 Rutland
39 Northamptonshire
40 Peterborough
41 Cambridgeshire
42 Norfolk
43 Suffolk
44 Essex
45 Southend-on-Sea
46 Thurrock
47 Hertfordshire
48 Central Bedfordshire ; Bedford
49 Luton
50 Milton Keynes
51 Buckinghamshire
52 Oxfordshire
53 Gloucestershire



54 Worcestershire
55 Herefordshire
56 South Gloucestershire
57 Bristol
58 North Somerset
59 Bath and North East Somerset
60 Wiltshire
61 Swindon
62 Berkshire
63 Greater London
64 Medway
65 Kent
66 East Sussex
67 Brighton & Hove
68 West Sussex
69 Surrey
70 Hampshire
71 Southampton
72 Portsmouth
73 Isle of Wight
74 Dorset
75 Poole
76 Bournemouth
77 Somerset
78 Devon
79 Torbay
80 Plymouth
81 Cornwall

Council functions post 1972

‘Place’ services

- Council housing
- Environmental health
- Leisure services
- Libraries and culture
- Planning
- Transport
- Roads and Footpaths
- Waste and recycling
- Parks and public places

‘People’ services

- Adult Care Services (e.g. older people, home care, residential care, learning and physical disabilities, mental health care)
- Childrens’ Services (e.g. schools, Looked After Children, Safeguarding, Special Educational Needs)
- Public Health

The council’s new Public Health responsibilities (from April 2013)

- Tobacco control
- Smoking cessation
- Health protection outbreaks
- Alcohol services
- Substance misuse services
- National Child Measurement programme
- Obesity services
- Nutrition initiatives
- Tackling social exclusion
- Reducing impact of environmental hazards
- Increasing physical activity
- NHS health checks
- Mental health promotion
- Dental health promotion
- Accident prevention
- Birth defect reductions
- Immunisation and screening programmes
- Sexual health services
- Contraception services
- Tackling domestic violence

Citizenship and Participation

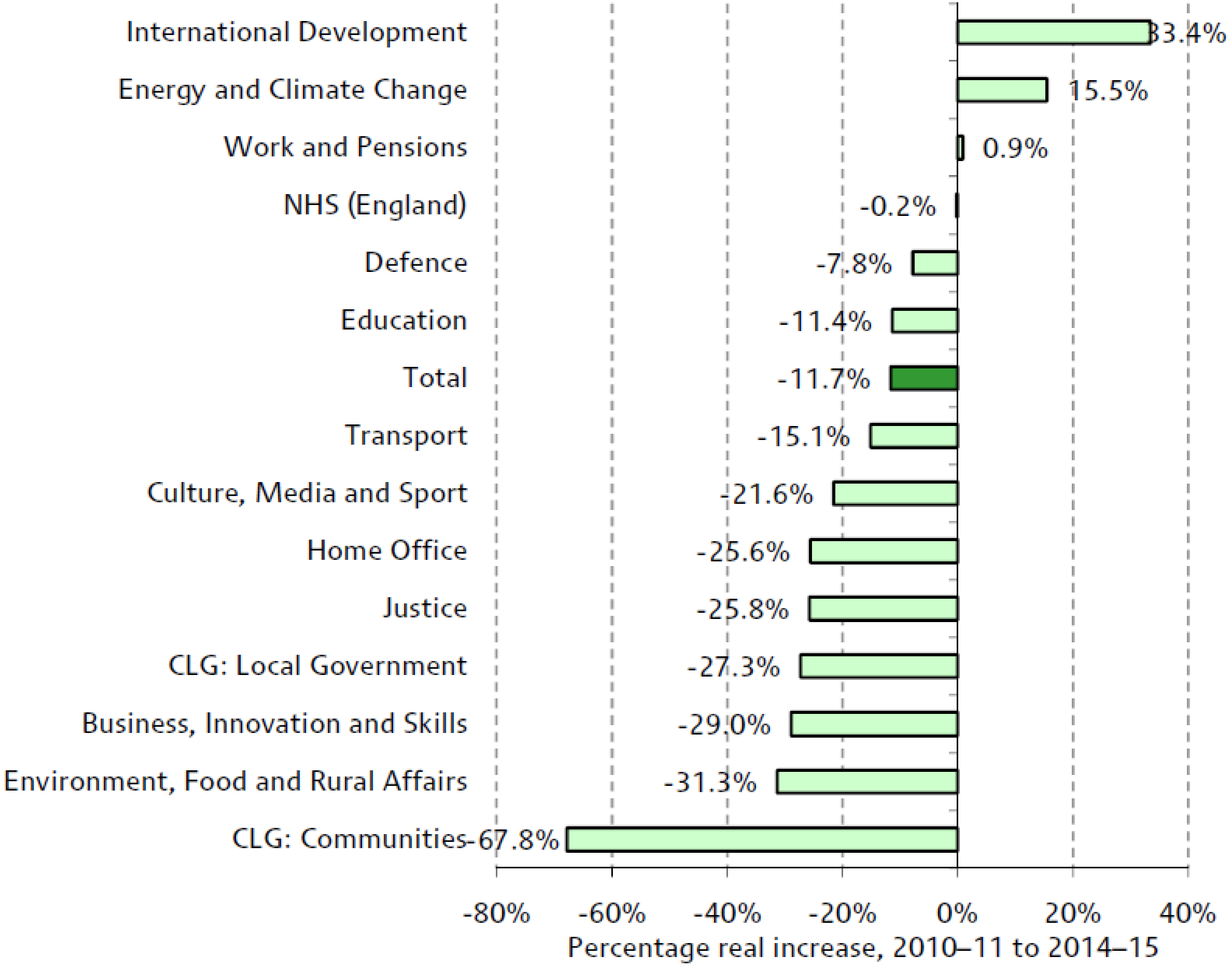
Democracy

- Local elections every year
- Politically shaped decision-making – through manifestos
- Engagement as 'citizens'
- Participation a 'civic responsibility'
- BUT
- Turnout 36% in 2014

Personalisation

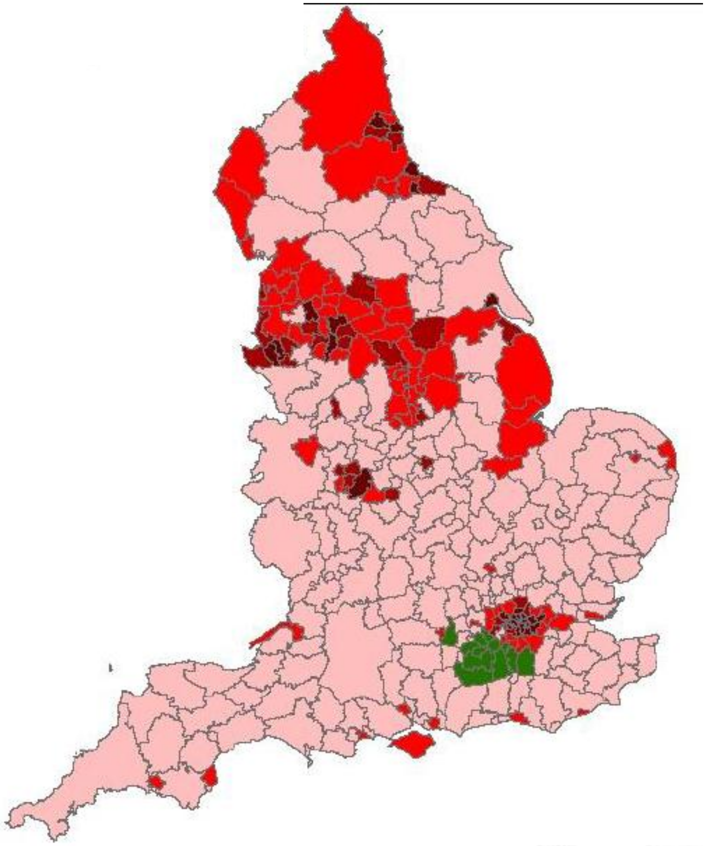
- Social care designed around the needs of individuals
- Professionally assessed needs
- Cash budget allocated ('direct payments')
- Can be spent on activities meeting assessed needs
- Drive for all recipients of social care to have personal budgets

Figure 6.4. Spending changes, by department

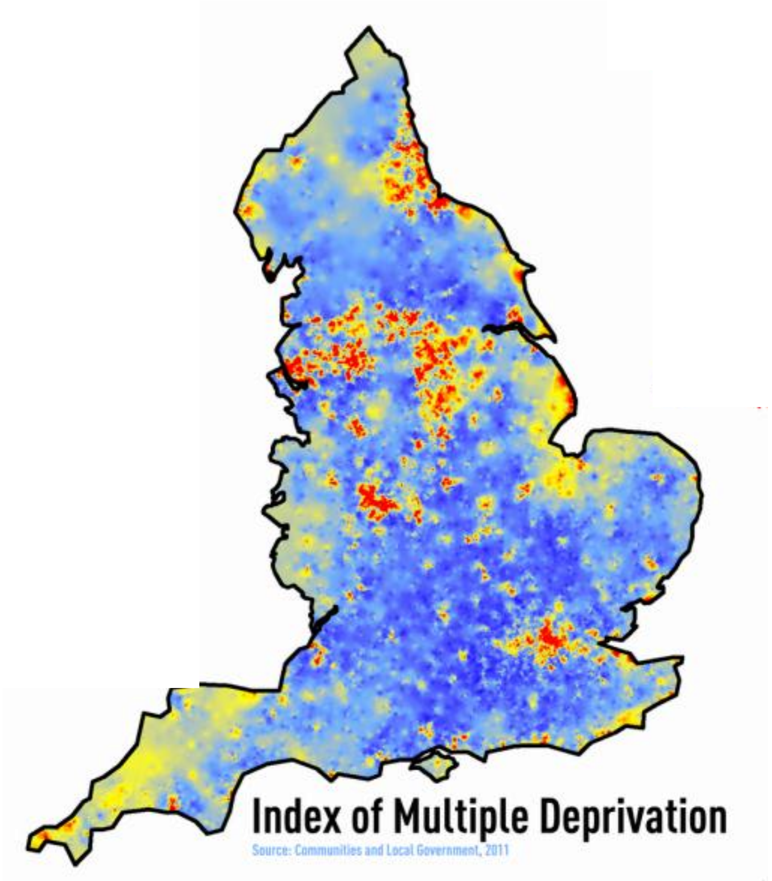


Austerity in action

Cumulative cuts to councils



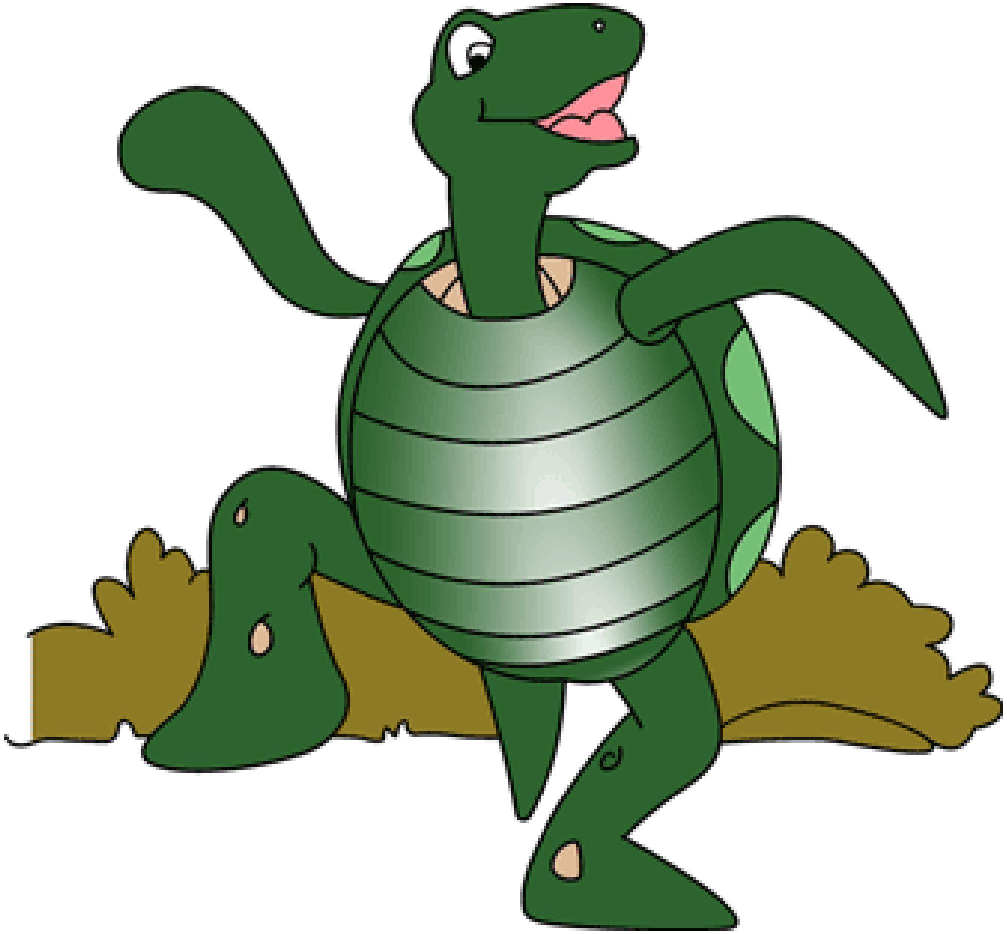
Index of Multiple Deprivation



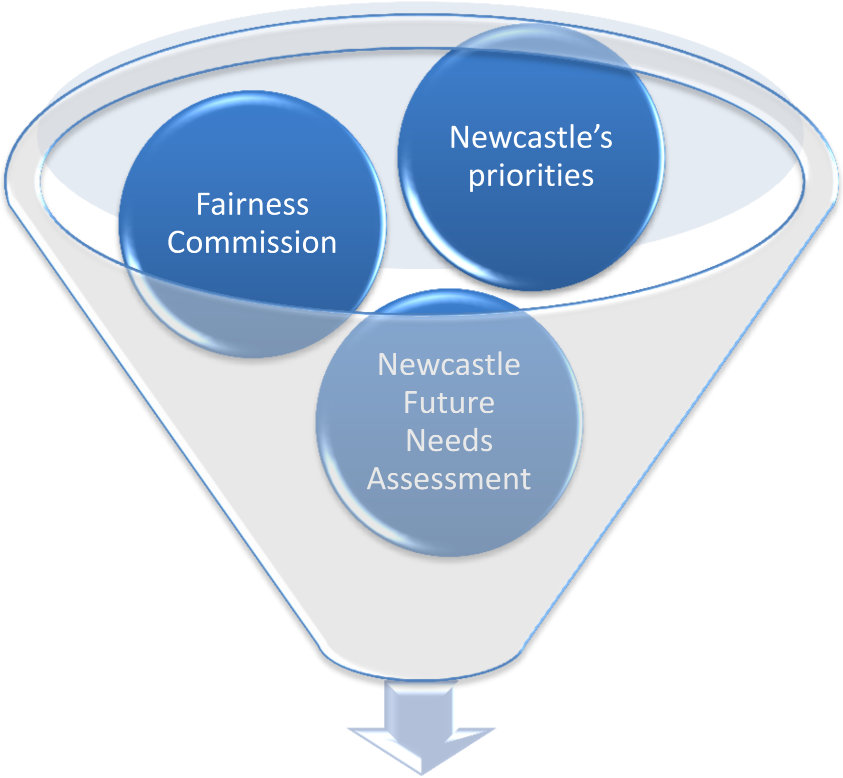
Source: Communities and Local Government, 2011

Health and Wellbeing Boards

- Proscribed membership: councillors, local authority and NHS commissioners, NHS England
- Can ‘influence’ commissioning plans
- Duty to develop a Joint Strategic Needs Assessment and
- Produce a Health and Wellbeing Strategy
- No resources, capacity or formal powers



Newcastle's approach to Health and Wellbeing



Fairness Commission

Newcastle's priorities

Newcastle Future Needs Assessment

Wellbeing for Life Strategy

Newcastle’s priorities

Working City

Decent Neighbourhoods

Tackling Inequalities

Co-operative Council ‘fit for purpose’

Why co-operation is essential

‘Self respect arises only out of people who play an active role in solving their own crises and who are not helpless, passive, puppet-like recipients of private or public services. To give people help, while denying them a significant part in the action, contributes nothing to the development of the individual. In the deepest sense it is not giving, but taking – taking their dignity. ***Denial of the opportunity to participate is the denial of human dignity and democracy.*** *It will not work.’*

Saul Alinsky

Newcastle Future Needs Assessment

"A different kind of assessment is needed… In line with ideas of social learning, such assessment should be based on dialogue, deliberation, and discussion between key stakeholders rather than a technical exercise done by experts. It would also call on a wide range of sources of knowledge, combining statistical data with the insights and experiential knowledge held by practitioners and the lay knowledge and experience of communities"

Lancet Commission (2012) "Shaping cities for health: complexity and the planning of urban environments in the 21st century"

Wellbeing for Life Strategy

- Working City – a healthy economy
- Decent Neighbourhoods – healthy places
- Decent Neighbourhoods – healthy communities
- Tackling inequalities through the impact of services

Some challenges…

- Culturally, and historically, public services are geared up to define needs and allocate resources to meet them
- This approach is financially (and morally?) unsustainable
- Power relationships – the idea that there are professionals and non-professionals – are changing

Changing power relationships

Old style ECG

iPhone monitor

Some challenges…

- Culturally, and historically, public services are geared up to define needs and allocate resources to meet them
- This approach is financially (and morally?) unsustainable
- Power relationships – the idea that there are professionals and non-professionals – are changing
- Communities often don’t feel heard or allowed to participate in issues that affect them
- New models of involvement – based on co-operative principles - can bridge these gaps

…and some questions for research

- Is the creation of new demand, through needs assessment, futile in a time of austerity?
- Where does the power lie in decision-making about research topics?
- How do research programmes have impact, given the complexity of decision-making?
- Does the idea of greater co-operation with non-academics weaken principles of academic rigour?
- Who else can help you engage communities and individuals in designing and delivering research programmes?
- What is research FOR?

Newcastle’s vision

“Good health until I die, vibrant and diverse social networks, equitable distribution of resources to achieve a thriving neighbourhood. A secure public environment”

“Looking well, feeling well, looking forward and never looking back. Not feeling neglected or invisible, not being patronised or marginalized”

“Good health, both mentally and physically. Having family and friends around to support me when needed and to talk things through. Social activity and sense of purpose”

“My own and my partners health, a warm, comfortable house, a friendly, safe neighbourhood, a city full of activities, a country that cares about people”