Integrating research into care: what does 'well-led' look like

Dr William van’t Hoff  
NIHR Clinical Director for NHS Engagement

NHS Engagement: what it means to us

“Helping the NHS and Care recognise that research is really important to improving health”

- Everyone involved in clinical research needs NHS Engagement and many undertake this in their routine work
- Helping NHS/Care see the value of research is vital for NIHR, charities, industry and our public
- A journey rather than a single step/achievement
- Patients and public are really important partners in delivering this message: Patient Research Ambassador Initiative

NHS Engagement: Key activities

1. Work with key NHS organisations/communities e.g. Care Quality Commission, R&D, NHS England
2. Link to research partners Professional bodies, AMRC, Life Sciences
3. Empower Patient Research Ambassadors
4. Listen, learn and support Research leaders on NHS Engagement Survey, Toolkits, Training and Platforms

Research and Quality of Care

Key aim of this CQC collaboration has been to help the NHS recognise the importance of high-quality research in improving the quality of care

- Encouraging Trust Boards to recognise value of clinical research
- Building capacity for research within the NHS
Research activity and survival in study of 511 patients with acute lymphoblastic leukaemia

Determined association between overall survival and trial recruitment in TYA patients with acute lymphoblastic leukaemia (ALL).

Strong relationship between participation in the main UK trial for ALL and survival in TYAs.

The difference in survival was highly significant, with a 17.9% superior survival at 2 years in trial patients compared with non-trial patients.

Research activity and survival in study of 200,000 patients with Colo-rectal cancer

Patients treated in Trusts with high research participation (≥16%) in their year of diagnosis had lower postoperative mortality (p<0.001) and improved survival (p<0.001).

Effects increased with sustained research participation, with a reduction in postoperative mortality of 1.5% (95% CI 0.5%–2.5%, p=1.7×10^{-6}) and an improvement in survival (p=10^{-9}; 5-year difference: 3.8% (41.0%–44.8%)) comparing high participation for ≥4 years with 0 years.

Participation in clinical trials improves outcomes in women’s health

- Systematic review and meta-analysis (Medline, Embase, the Cochrane Library, and PsycInfo)
- 21 relevant studies (20,160 women, 4759 outcome events)
- Trial participants, compared with non-participants, had 25% better odds of improved outcomes on average (OR 0.75; 95% CI 0.64-0.87; I² = 64.3%)
- Women participating in RCTs on average experienced better outcomes compared with those outside trials.

(Obstet & Gynaecol. 2017 May;124(6):863-871)

The correlation between NHS trusts’ clinical trial activity, mortality rates and CQC ratings

- A retrospective cross-sectional study of NIHR activity at 129 NHS Trusts
- Research activity was controlled for Trust size by dividing it by clinical staffing levels
- Significant association between the number of studies and participants with both SHMI score and CQC rating
- Number of participants recruited into interventional studies shows a significant correlation with better CQC ratings (standardised coefficient beta 0.26, P-value 0.003) and lower SHMI scores (standardised coefficient beta -0.50, P-value 0.001)

Other benefits of research for the NHS

Research:

• underpins the evidence we need to provide best care
• is empowering:
  Patient Research Experience Survey 2017-18
  a. 87% of patients have a very good experience of research…. “I take part in research. If I don’t… how is the NHS to go forward?”
  b. Staff “friendly, professional, knowledgeable, available and respectful

Background to work with CQC

Late 2017, the CMO made the following recommendation in her annual report:

“I recommend that CQC should have as one of its characteristics of a well-led organisation an assessment of support for opportunities for patients to join cutting-edge research projects and clinical trials.”

In 2017: CRN/CQC high level meeting agreed the principle that clinical research had a positive impact on the quality of patient care*

Partnership established between CQC, CRN, HRA, MHRA and patient reps to take work forward as a project.

Clinical research isn’t just a ‘nice to do’ exercise in the NHS - it is now a key part of improving patient care

Partnership

Patients have been a key catalyst for the partnership and its progress, having equality at the table

R&D leadership have been major contributors to the partnership including: Maria Thornton, Christine McGrath, Lee Tomlinson, Alison Thompson, Emma Stratful, Ashley Solieri, Matthew Peak, David Wynick

3 levels of support for clinical research

Equity
Facilitation
Awareness
The 2018 update of the Well Led Framework now includes research questions (Section W8).
[https://www.cqc.org.uk/sites/default/files/20180921_9001100_trust-wide_well-led_inspection_framework_v5.pdf]

‘Brief Guide: Research in NHS Trusts’ was written by the partnership and has now been published by the CQC internally. It is in two parts:

- **Part 1**: Background including related policy, evidence, and operational context of research in the NHS.
- **Part 2**: Details on what ‘good’ looks like and what to look for within the three aspects.

Inspectors will also have access to Experts in NHS research attached to the CQC.

A question included on whether inpatients have been offered a research opportunity during their last hospital stay.

- Live now, we expect responses from approximately 80,000 patients in 150 Trusts.

We are scoping a data-based measure of research activity in NHS Trusts.

- We are working with the CQC Academy to develop an online learning tool on research in the NHS for Inspectors.
Data indicator: sample data on number of studies

Clinical research is now in the CQC remit for inspection assessments. This is about its relevance to patient care.

Questions to consider:
- how does a patient entering or staying in the hospital see research?
- what do staff know or think about research at all levels?
- how does the hospital culture and processes enable research to happen?
- how does the hospital lead research?

A whole system for Well Led research in the NHS

What NHS Trusts could consider

Board: strategy, R&D leadership, governance and oversight, operational delivery.
Staff: aware, trained, opportunities
R&D: team, research awareness, facilitation
Patients and public: research awareness
Partnerships: NIHR Local Clinical Research Network, Charities
May be best to stick to structure of the 3 levels as it pertains to Trust activity
-Roger Steel
, 13/11/2018
This video from Nottingham University Hospitals NHS Trust emphasises the importance of research in improving patient outcomes.

Further information

- About the CQC Project and FAQs

- CQC Well Led Framework

- Contact: Sarah Birch, Project Support
  Email: sarah.birch@nihr.ac.uk

Feedback

- It is great that we are engaging with the CQC. It would be useful to know what ‘good looks like’

- Could be a great lever for R&D/R&I departments who perhaps don’t always feel heard or prioritised within their organisation

- How do we support Trusts struggling to do research?

- Research should be part of all staff inductions

- No more refusing that research is a core part of service delivery!