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A Centre Of Research for Nurses and Midwives

NHS Guy's and St Thomas' NHS Foundation Trust

Public and patient involvement and engagement in research

Dr Suzanne Bench PhD

Director of Nursing, Nurse and Midwife led Research: Guys and St Thomas NHS Foundation Trust

Professor of Critical Care Nursing: London South Bank University

Three elements of inclusivity

- Public and Patient Involvement and Engagement
- Diversity in research participation
- Engaging clinical nurses and midwives

Public and Patient Involvement & Engagement in Research

Research carried out
‘with’ or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them
(NIHR INVOLVE)

‘Active Involvement’

Involvement round the research cycle

Question Generation workshops
Research Partnerships

Refining research question(s)

Reviewing drafts, summaries and ethics applications
Co-producing research proposals

Developing research proposal

Steering and advisory group members
Service user researchers
Data gatherers

Undertaking research

Coding
Interpreting
Discussing

Analysing research findings

Through service user organisations
Co-presenting findings
Co-authorship of papers

Dissemination of findings

Using evidence
Implementing treatments
Campaigning for change

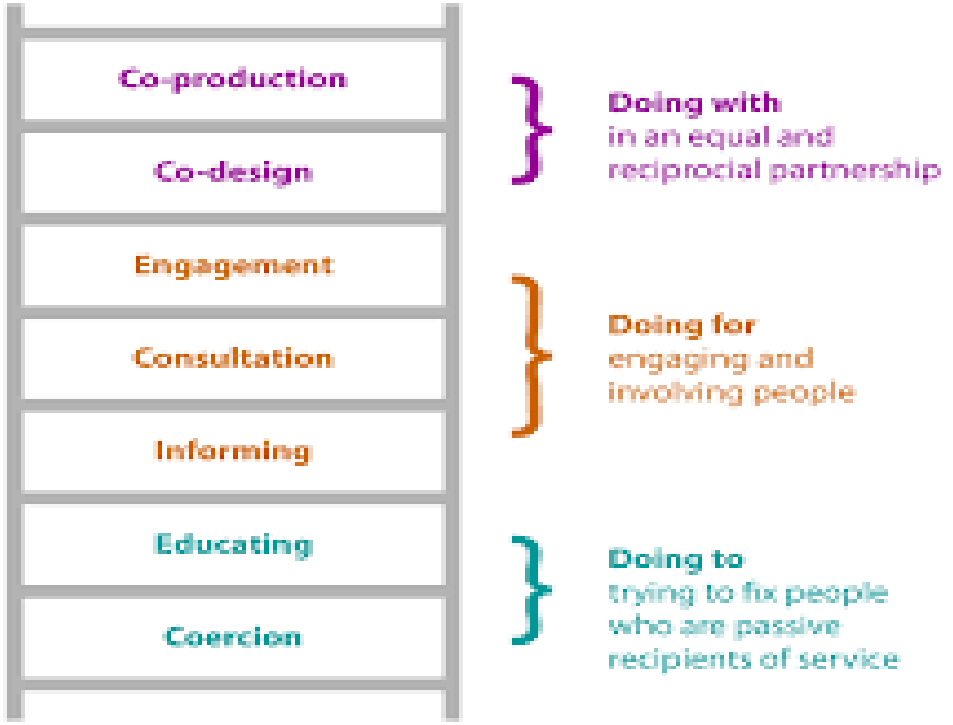
Implementation of findings

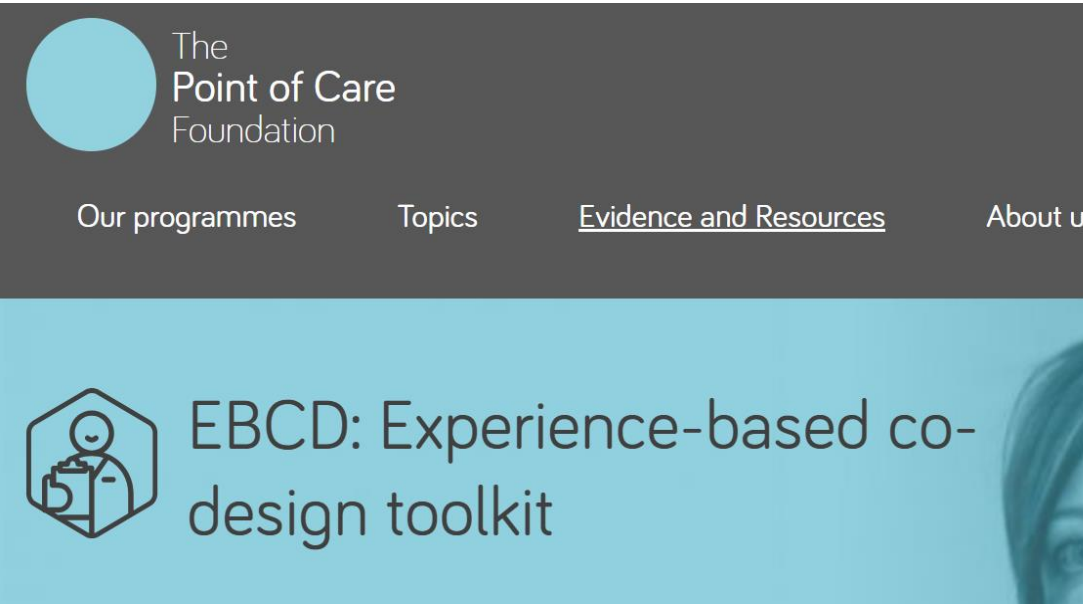
Funding panels
Prioritisation partnerships
Campaigning groups

Identifying and prioritising issues

Participatory methodologies

- Co-Design
- Co-Creation
- Co-Production
- Experience Based Co-Design





REVIEW ARTICLE | Open Access

Mapping definitions of co-production and co-design in health and social care: A systematic scoping review providing lessons for the future

Daniel Masterson PsyD, Kristina Areskoug Josefsson PhD, Glenn Robert PhD, Elisabeth Nylander MSc, Sofia Kjellström PhD

First published: 23 March 2022 | https://doi.org/10.1111/hex.13470 | Citations: 17

To enable involvement, PPI needs to be funded adequately, opportunities need to be clearly communicated, and support needs to be available for researchers and PPI contributors

Doing PPI just for the sake of it can discourage researchers and disenfranchise people…PPI should be relevant and meaningful for the research and the people involved.

PPIE in Critical Care

International Journal of Consumer Studies

Original Article

The nature and extent of service user involvement in critical care research and quality improvement: A scoping review of the literature

Suzanne Bench, Erica Eassom, Konstantina Poursanidou

First published: 01 November 2017 | https://doi.org/10.1111/ijcs.12406 | Citations: 11

Theme 1: Making it happen	Theme 2: Overcoming hurdles	Theme 3: It helps	Theme 4: Respect and value
Nature of involvement	Meeting logistics	Personal benefits	Support, encouragement and feedback
Inclusivity and flexibility	Health status	Wider impact	Training needs
Providing opportunity			Shared language

GUEST EDITORIAL
doi: 10.1111/nicc.12418

Involving patients and families in critical care research and quality improvement

Nurs Res. 2020 Sep/Oct;69(5):367-375. doi: 10.1097/NNR.0000000000000443.

Patient and Family Member Experiences in Critical Care Research and Quality Improvement Projects

Suzanne Bench [1], Alison O'Shea, Annette Boaz

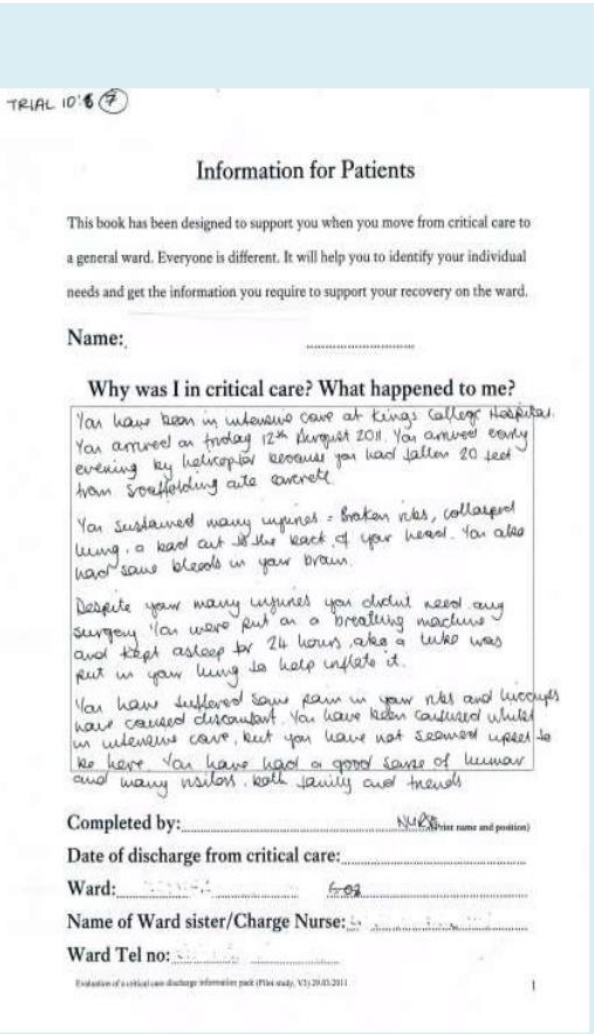
- **Need for flexibility, inclusivity and transparency**
- **Importance of individualised support and training**
- **Vital role of project leads in making people feel valued and equal partners in the process**

F-ACT (Fatigue After Critical Illness)

Fatigue after Critical Illness

- We are looking for people to help us develop strategies to manage fatigue after critical illness.
- We would like to hear from:
  - **ICU survivors** who have suffered from **fatigue**
  - **Family/informal carers** of ICU survivors
  - **Health and social care professionals** in critical care/ICU follow-up clinics
  - **Clinical psychologists** in ICU
  - **Community nurses/GPs/social workers** caring for ICU survivors
- Could you help?
- If you are interested, please contact eleanorbrown@brookes.ac.uk

User Centred Critical care Discharge Information (UCCDIP)



TRIAL ID: 6 (7)

Information for Patients

This book has been designed to support you when you move from critical care to a general ward. Everyone is different. It will help you to identify your individual needs and get the information you require to support your recovery on the ward.

Name:

Why was I in critical care? What happened to me?

You have been in intensive care at Kings College Hospital. You arrived on friday 12th August 2011. You arrived early evening by helicopter because you had fallen 20 feet from scaffolding onto concrete.

You sustained many injuries - broken ribs, collapsed lung, a bad cut at the back of your head. You also had some bleeds in your brain.

Despite your many injuries you didn't need any surgery. You were put on a breathing machine and kept asleep for 24 hours, also a tube was put in your lung to help inflate it.

You have suffered some pain in your ribs and hiccups have caused discomfort. You have been confused whilst in intensive care, but you have not seemed upset to be here. You have had a good sense of humour and many visitors, both family and friends

Completed by: (Print name and position)

Date of discharge from critical care:

Ward:

Name of Ward sister/Charge Nurse:

Ward Tel no:

Evaluation of a critical care discharge information pack (Pilot study, V3) 29.03.2011 1

You have been in intensive care at XXX Hospital. You arrived on Friday 12th August 2011. You arrived early evening by helicopter because you had fallen 20 feet from scaffolding onto concrete.

You sustained many injuries = Broken ribs, collapsed lung, a bad cut to the back of your head. You also had some bleeds in your brain.

Despite your many injuries you didn't need any surgery. You were put on a breathing machine and kept asleep for 24 hours, also a tube was put in your lung to help inflate it.

You have suffered some pain in your ribs and hiccups have caused discomfort. You have been confused whilst in intensive care, but you have not seemed upset to be here. You have had a good sense of humour and many visitors, both family and friends

UK Standards for Public Involvement

Better public involvement for better health and social care research

- A set of UK standards designed to improve the quality and consistency of public involvement in research
- Developed over 3 years by a 4-nation partnership and tested by 40+ individuals, groups and organisations during a year-long pilot programme.
- The standards are for everyone doing health or social care research. They can also be used in other contexts too.
- They are a description of what good public involvement looks like and are designed to support self-reflection and learning
- Reflective questions accompany each Standard to encourage users to think about their public involvement plans and actions
- They provide guidance and reassurance for users working towards achieving their own best practice.

NIHR | National Institute for Health Research
CHIEF SCIENTIST OFFICE
Ymchwil Iechyd a Gofal Cymru Health and Care Research Wales
HSC Public Health Agency

PPI Resources

- UK Standards for Public Involvement website: https://sites.google.com/nihr.ac.uk/pi-standards/home https://sites.google.com/nihr.ac.uk/pi-standards/home://www.invo.org.uk/
- Learning for Involvement website: https://www.learningforinvolvement.org.uk http://learningforinvolvement.org.uk/
- Health Research Authority – Public Involvement: https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/ h
- The Service User Advisory Group (NIHR Maudsley Biomedical Research Centre only): https://www.maudsleybrc.nihr.ac.uk/patients-public/support-for-researchers/
- Briefing notes for researchers - public involvement in NHS, health and social care research | NIHR

PPI impact log video guidance - YouTube

NIHR's new Centre for Engagement and Dissemination

The NIHR has launched a new Centre for Engagement and Dissemination that brings together its activities in patient and public involvement, engagement and participation with its strengths in research dissemination.

Diversity of Research Participants

Research Participation: The Issue of Diversity

- [Diversity in Research Participation: why it's important | Recruitment Services (ucsf.edu)]

[NHS Accelerated Access Collaborative » Increasing diversity in research participation: A good practice guide for engaging with underrepresented groups (england.nhs.uk)]

Improving representation in maternity research: The REPRESENT Study

This participatory action research is developing a toolkit/guidance for those who recruit to research in maternity settings to improve participation from ethnic minority groups.

Holly Lovell: NIHR DCAF

How can we enhance LGBTQI+ communities to participate in COVID/Infectious Diseases Reseach?

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Guy's and St Thomas'
NHS Foundation Trust

1 Introduction

Evidence shows that work is needed to address the barriers and negative connotations of LGBTQI+ individuals accessing healthcare (Stonewall, 2018). This research proposal would be a key aspect of academic research that would enable myself to recognise and discover why there is apprehension to undertake research trials from LGBTQI+ participants, and analyse whether there is a wider issue such as unconscious bias on recruitment or other key issues that could be improved.

2 Objective

- Improve understanding of research participation through collecting LGBTQI+ demographics on research recruitment.
- Recognise perceptions from LGBTQI+ communities as to why they don't take part in research.

3 Methodology

Observational design, in the form of a cross sectional study to look at which trials within the COVID clinical research team do collect data for LGBT identifiers such as sexuality or gender. There is no control group and no intervention for my research proposal.

One in seven LGBT people (14%) avoid seeking healthcare for fear of discrimination from staff (Stonewell et al. (2018)

[Increasing diversity in research participation: A good practice guide for engaging with underrepresented groups (england.nhs.uk)]

2.1. Pre-research planning

Learn and develop relationships to support engagement work

- Learning from communities
- Recruitment
- Establishing trust
- Incentives
- Preparation

2.2. During research

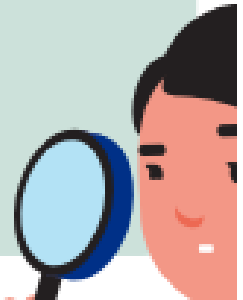
Involve and respect differences

- Facilitation
- Active listening
- Inclusion
- Respect
- Check assumptions
- Wellbeing

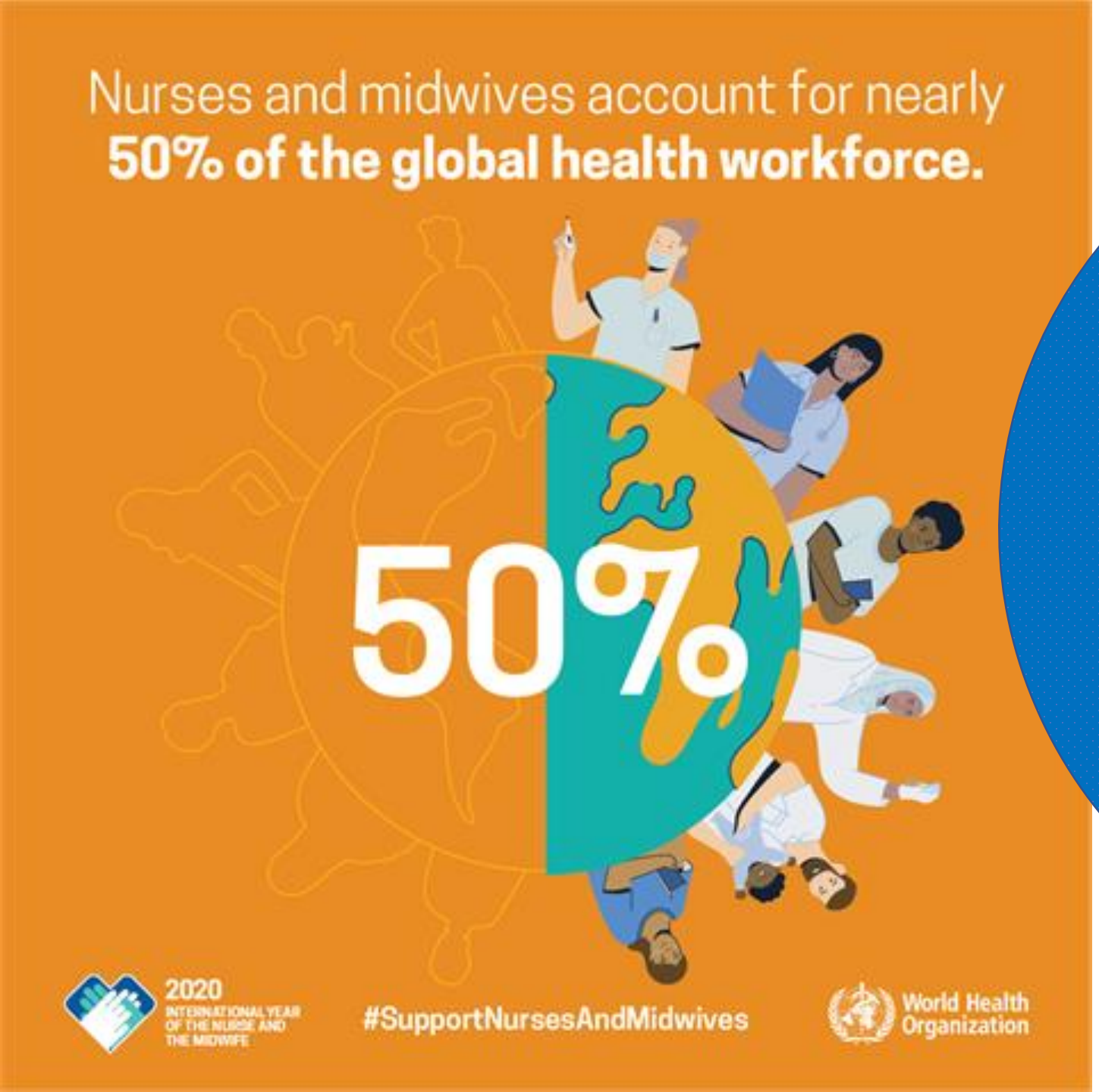
2.3. Post research

Feedback and amend

- Maintain relationships
- Long-term trust
- Positive legacy



Engaging clinical nurses and midwives



"Research-active organisations have the potential to achieve better patient outcomes"

CQC

All health service staff face barriers to research. However, research access and capacity varies across professions:

Lacking confidence in research knowledge and skills was reported by...

33% of nurses and midwives

38% of allied health professionals

23% of doctors

Barriers in getting sufficient research training in NHS organisations was reported by...

36% of nurses and midwives

38% of allied health professionals

25% of doctors

Peckham et al. (2021). **Creating Time for Research: Identifying and improving the capacity of healthcare staff to conduct research**.

Professor Jo Cooper: Head of Nursing Research – Research Transformation: CNO-England

Professor Alison Richardson Head of Nursing Research, Academic Leadership and Strategy: CNO-England

Professor Ruth Endacott: NIHR Director of Nursing & Midwifery

Professor Jane Sandall CBE
Head of Midwifery Research: NHSE

NHS 75 England

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Making research matter: Chief Nursing Officer for England's strategic plan for research

Date last updated: 17 May, 2023

Maternity, Nursing, midwifery and care

Chief Midwifery Officer for England's strategic plan for research

NMResearch

Home | About

Nursing and Midwifery Research Portal

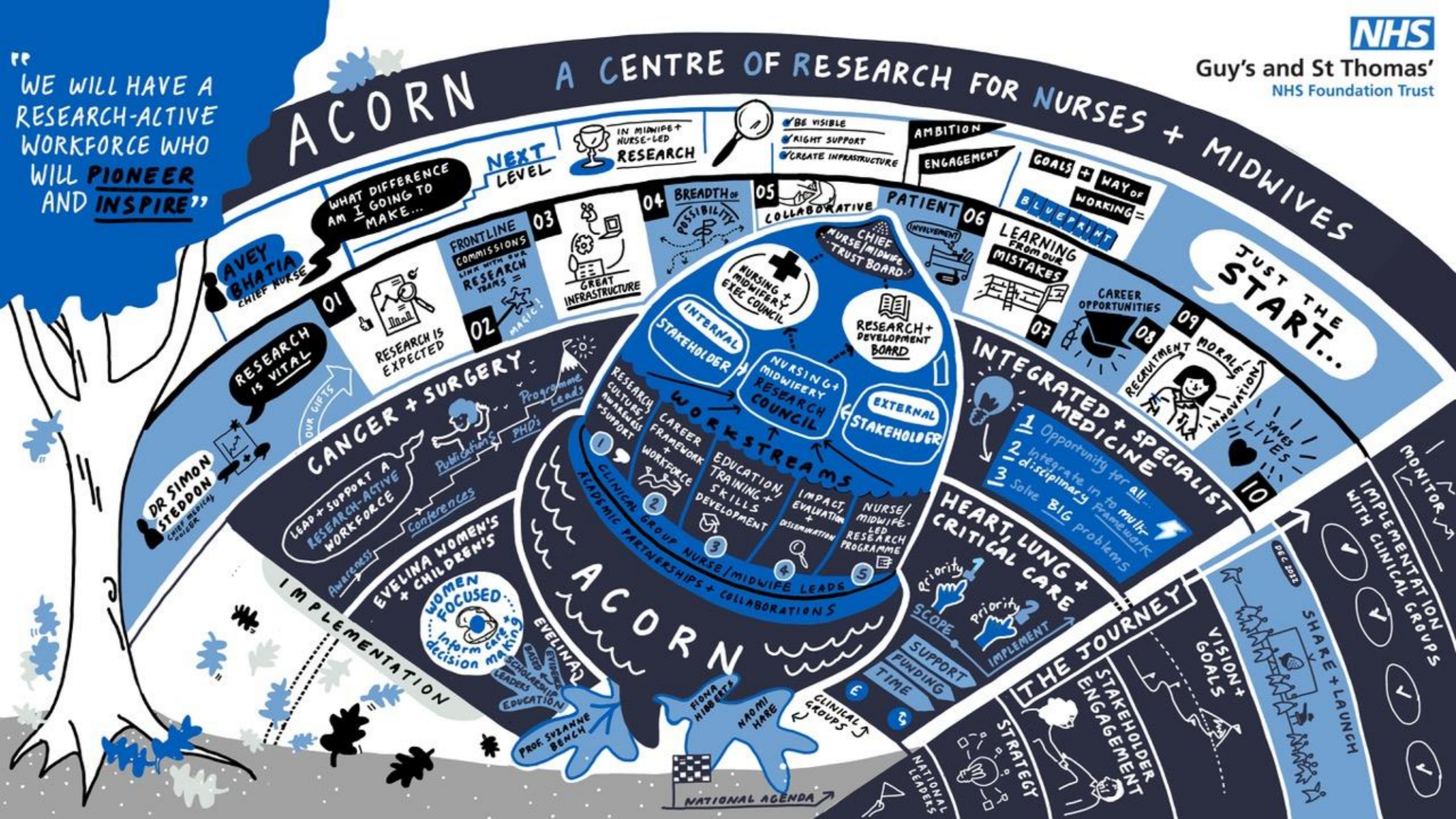
The Nursing and Midwifery Research Portal has been set up to expand capacity and support the development of a skilled clinical academic research workforce in nursing and midwifery professions.

NIHR | National Institute for Health and Care Research

Health and Care Professionals | Researchers | Patients and the Public | Partners and Industry | About us

Senior Research Leader - Nursing & Midwifery Programme

The NIHR Nursing and Midwifery Incubator


"WE WILL HAVE A RESEARCH-ACTIVE WORKFORCE WHO WILL PIONEER AND INSPIRE"
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A CENTRE OF RESEARCH FOR NURSES + MIDWIVES
NHS
Guy's and St Thomas'
NHS Foundation Trust
AVEY BHATIA
CHIEF NURSE
WHAT DIFFERENCE AM I GOING TO MAKE...
NEXT LEVEL
IN MIDWIFE + NURSE-LED RESEARCH
BE VISIBLE
RIGHT SUPPORT
CREATE INFRASTRUCTURE
AMBITION
ENGAGEMENT
GOALS + WAY OF WORKING = BLUEPRINT
JUST THE START...
01 RESEARCH IS EXPECTED
02 MAGIC!
FRONTLINE COMMISSIONS LINK WITH OUR RESEARCH TEAMS =
03 GREAT INFRASTRUCTURE
04 BREADTH OF POSSIBILITY
05 COLLABORATIVE
PATIENT INVOLVEMENT 06
07 LEARNING FROM OUR MISTAKES
08 CAREER OPPORTUNITIES
09 RECRUITMENT MORALE INNOVATION
10 SAVES LIVES
RESEARCH IS VITAL
DR SIMON STEDDON
CHIEF MEDICAL OFFICER
OUR GIFTS
CANCER + SURGERY
LEAD + SUPPORT A RESEARCH-ACTIVE WORKFORCE
Publications
Programme Leads
PHDs
Conferences
Awareness
EVELINA WOMEN'S + CHILDREN'S
WOMEN FOCUSED
Inform care + decision making
EVELINA EVIDENCE BASED SCHOLARSHIP LEADERS EDUCATION
IMPLEMENTATION
ACORN
NURSING + MIDWIFERY EXEC COUNCIL
CHIEF NURSE/MIDWIFE TRUST BOARD
INTERNAL STAKEHOLDER
RESEARCH + DEVELOPMENT BOARD
NURSING + MIDWIFERY RESEARCH COUNCIL
EXTERNAL STAKEHOLDER
WORKSTREAMS
1 RESEARCH CULTURE/AWARENESS + SUPPORT
2 CAREER FRAMEWORK + WORKFORCE
3 EDUCATION, TRAINING + SKILLS DEVELOPMENT
4 IMPACT, EVALUATION + DISSEMINATION
5 NURSE/MIDWIFE-LED RESEARCH PROGRAMME
ACADEMIC PARTNERSHIPS + COLLABORATIONS
CLINICAL GROUP NURSE/MIDWIFE LEADS
PROF. SUZANNE BENCH
FIONA HIBBERT
NAOMI HARE
CLINICAL GROUPS
NATIONAL AGENDA
INTEGRATED + SPECIALIST MEDICINE
1 Opportunity for all...
2 Integrate in to multidisciplinary framework
3 Solve BIG problems
HEART, LUNG + CRITICAL CARE
priority SCOPE
priority IMPLEMENT
SUPPORT
FUNDING
TIME
£
THE JOURNEY
STRATEGY
NATIONAL LEADERS
STAKEHOLDER ENGAGEMENT
VISION + GOALS
DEC 2022
SHARE + LAUNCH
IMPLEMENTATION WITH CLINICAL GROUPS
MONITOR

GSTT Research Internship

- 13 nurses and midwives (2021)
  - X1 DCAF interview
  - X1 Pre doctoral bridging scheme
  - X1 PCAF
  - X1 internal funding application
  - X1 MRES
  - X2 PCAF applications in progress

'a really great opportunity to dip your toes into research or if your prefer, an opportunity to leap into the sea of clinical research academia'

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- Identify local NHS priorities for nursing and midwifery
- Clinical-academic advisory groups for N&M with partner trusts
- Speed dating or sandpit type activities with local Trusts
- Courses focusing on developing research proposals
- Clinical-academic project groups

- Be curious
- Discuss research engagement at induction, appraisal and in team meetings
- Journal clubs and forums
- Link with academics
- Create internal and external joint appointments for research and practice
- Access internal and external opportunities

Inclusivity in Research: Final Thoughts

- Inclusivity is when everyone is participating and participation is comprehensive across the multiple stages of the research
- To develop inclusive research, we need to create a research culture that includes, rather than excludes, under-represented groups.
- This includes those designing and delivering research as well as those who participate

Thank you for listening
Any Questions?

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