# NHS England's Research Needs Assessment 2018

NHS England in partnership with the National Institute for Health Research

# Document Title: NHS England's Research Needs Assessment 2018

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# Contents

# 1 Background

The National Institute for Health Research (NIHR) is committed to maximising the potential impact of research that it funds for patients and the public. This means ensuring that it answers the right questions at the right time in the right way, delivering the research efficiently and publishing the results in full in accessible and unbiased reports.

The first way to add value in research is to ensure that the questions being researched are those most important to patients, the public and clinicians. This is achieved in many ways, from public involvement at every stage of the research pathway, through commissioning research against questions explicitly identified and prioritised with those that plan, deliver and use health services.

In November 2017, NHS England and the NIHR published a joint statement, endorsed by the NHS England board, outlining their commitment to "Twelve actions to support and apply research in the NHS". One of these actions was a commitment to better articulate the NHS England's national and local research needs so that wherever possible, policy and practice can be informed by high-quality and timely research evidence or information synthesis.

Recognising that NHS England need to articulate research needs effectively and the mechanisms to identify and transmit these priorities to relevant bodies should be clearly described, NHS England have worked in partnership with the Department of Health and Social Care (DHSC) and NIHR over the last six months to start to define the evidence that NHS England needs to deliver its programmes of work, enhancing evidence-based commissioning and improving outcomes for patients, the public and NHS services.

This publication outlines the first stage of this work, summarising the information and areas for research identified by NHS England's six national priority programmes (Urgent & Emergency Care (UEC), Mental Health, Primary Care, Cancer, Diabetes and Specialised Commissioning), and the medical and nursing directorates. These provide an early signal of potential research requirements across the wider clinical portfolio, while recognising that some issues require further refinement and development. It identifies NHS England's assessment of the research needs at a single point in time and forms part of an ongoing collaboration between NHS England and the NIHR.

Because of NIHR's multiple stakeholders and the dynamic nature of research needs, this publication does not provide an exhaustive list of either NHS England's potential research needs or NIHR's research priorities. Research themes that are not highlighted in this publication may emerge through NIHR's work with other key stakeholders or through NHS England's ongoing examination and refinement of its research needs, including through development of the NHS' Long-Term Plan.

# 2 Approach to identifying NHS England's research needs

## 2.1 National Priority Programmes

NHS England has worked closely with NIHR and DHSC colleagues, as well as national clinical leaders, to define areas where better information or research is required. A number of principles guided our work:

- Research should only be undertaken if it will provide rigorous and relevant outcomes to improve NHS services, and people will still be interested in the result and accept the conclusion once the evidence is generated
- New research should only be undertaken in areas where there are defined evidence gaps and the need for the research can be clearly articulated.
- Where research exists but is not accessible to policy makers, work should be undertaken to synthesise and disseminate findings of existing work to assist translation and implementation of findings.
- The research needs identified should offer value for money; the costs of investigating should be outweighed by the clinical and financial benefits of having the evidence in the future
- The needs we identify should help address key objectives of the Five Year Forward View and other relevant national policy documents (for example, the Five Year Forward View for Mental Health and the Cancer Taskforce Recommendations).

NHS England's policy development draws on the input of a wide range of stakeholders, including charities and patients and the public. NIHR also involves a wide range of stakeholders, including members and representatives of the public as research priorities and projects are taken forward.

In early 2018, NHS England convened a series of workshops to further develop and prioritise the research needs across each of the six specialty areas. These interactive workshops comprised a broad range of individuals from across NHS England, NIHR as well as a range of external stakeholders. Specifically, each workshop:

- Identified broad themes of enquiry important to delivering or refining key national policies and programmes, whose objectives have been developed with input from a broad range of stakeholders
- Undertook to refine some of these broad themes into more targeted statements of research need
- Helped to identify where published evidence or research already exists in the NIHR portfolio, and where further synthesis by NHS England, or more effective dissemination may be required

- Considered where immediate action could be taken to meet the highest priority and most urgent research needs.

We cross-referenced the initial long-list of research needs that emerged from these workshops with the relevant James Lind Alliance (JLA) Priority Setting Partnerships (PSPs) to refine or extend our research needs. In addition, for those research needs identified by Specialised Commissioning, a 2 week period of stakeholder testing was undertaken to test the topics and specific focus of priorities prior to their agreement by a final prioritisation panel.

Finally, a number of NIHR programme leads then assessed the 'face validity' of the proposed research needs.

## 2.2 Wider Clinical Portfolio

As this is the first such exercise that the NIHR and NHS England have undertaken together, the initial focus was around the six priority programmes, with only a high-level overview of remaining areas undertaken in partnership with NHS England's Medical and Nursing Directorates. We acknowledge this will not reflect the entirety of research needs and we are planning to refine our approach to cover additional clinical areas in the coming years.

The NHS England national clinical directors and chief professional officers have agreed a set of research and information needs, which currently present the most pressing need for evidence. As with the issues identified by NHS England's priority programmes, these are neither a final nor a complete list, but provide a view at a point in time.

## 2.3 Outcomes

The result of this process led to the identification of 100 areas of potential research interest. Unsurprisingly, there was significant overlap between the research needs identified through this process and existing work underway within the NIHR portfolio. A number of areas where immediate new activity could be undertaken were also identified. An initial assessment by NIHR categorised each of the needs as follows:

| | **Initial assessment** | **Number of research needs identified by UEC, Diabetes, Cancer, Primary Care and Mental Health** | **Number of Research Needs identified by Specialised Commissioning** | **Total** |
|---|---|---|---|---|
| **A** | Areas NIHR are already taking forward, for example: already advertising against this area, under review by the relevant prioritisation committee, research brief already in development | **15** | **3** | **18** |

| | | | | |
|---|---|---|---|---|
| **B** | Relevant evidence exists and / or is being addressed through current NIHR research | **16** | **8** | **24** |
| **C** | Further development with NHS England needed to articulate the tractable research question in the context of the existing evidence base, and prioritise | **18** | **40** | **58** |

We cross-referenced the initial long-list of research needs that emerged from this work with the relevant JLA PSPs to refine or extend our research needs. A number of NIHR programme leads then assessed the 'face validity' of the proposed research needs.

# 3 NIHR research commissioning activity

## 3.1 Immediate Activity

Of the 18 areas for research currently being taken forward by NIHR (see **Appendix 1**, category **A**), immediate activity includes the commissioning of:

**Two rapid evidence syntheses and one rapid evaluation:**

- A meta-review on compliance with digital systems (Urgent & Emergency Care).
- A rapid evidence review to synthesise the existing evidence on:
  - Effectiveness, benefits and risks of different digital models of interaction and consultation between patients and primary care.
  - How digital channels compare with telephone and face-to-face channels for different patients and conditions, their impact on GP capacity and utilisation, patient convenience and experience. (Primary Care).
- A rapid evaluation to identify the most effective collaborative delivery models of primary care, their impact on costs in the system, the barriers and facilitators to such networks (Primary Care).

**Development of a number of NIHR calls for research:**

- What is the clinical and cost-effectiveness of continued treatment in early intervention in psychosis (EIP) compared to usual care (discharge at 3 years) on relapse rate, suicidal behaviours, and symptoms. (Mental Health).
- The evaluation of emerging models from Sustainability and Transformation Partnerships (STPs)/Accountable Care Organisations (ACOs)/Integrated Care Systems (ICSs) that are integrating physical and mental health:

service models, staff mix, staff skills and competencies, levers, service user implications. What are the particular mechanisms that ensure delivery of cost effective models. What are the barriers and facilitators? (Mental Health).

- Model of stroke thrombectomy care based upon bypass model (mothership) versus decentralised model (drip and ship) – is a trial feasible and what would it look like? (Medical Directorate).
- Evaluation of the roll out of digital 111 across the four NHS England regional pilots. What is the effect of digital 111 on the rest of the Urgent & Emergency Care landscape and specifically on the telephone use of 111? (Urgent & Emergency Care).

Of the remaining areas for research within category **A**, a number are being considered further by the relevant NIHR prioritisation committee, while several other more well-defined research issues are being developed into potential commissioned research calls. These will be prioritised for advertisement through the relevant NIHR research programmes usual processes.

### 3.2 Medium/Longer Term Activity

For the areas for research not being taken forward by NIHR (category **C**), NHS England, with support from NIHR over the next 12 months, will:

1. Refine and focus the issues into tractable research questions in the context of the existing evidence base, and prioritise in accordance with the forthcoming NHS Long-Term Plan

2. Review those research areas where research evidence already exists before either new research could be commissioned by NIHR or where the evidence is already sufficient to allow active dissemination to key decision makers.

The initial area of focus for this review and refinement will be Specialised Commissioning, where we will work with clinical leads and NIHR over the next 6 months. Alongside this, NHS England and NIHR will establish continuous collaborative processes for identifying, evaluating and prioritising research needs as they emerge, to refine and focus these into specific, tractable research questions that have the most impact.

## 4 Continued collaboration with NIHR

The work to date represents an element of NHS England's research needs at a single point in time. An ongoing collaboration with NIHR and other research funders is required to ensure NHS England identifies the research evidence it needs to commission the most cost-effective and clinically-effective services for patients. This process will draw on the expertise of wider stakeholders such as patients and public, the voluntary sector, evidence users and academia.

NHS England's existing internal capabilities in prioritising policy research needs, which already draw on expert input from its operational research and evaluation unit, will provide an ideal complement to this, helping it to be more directive across the spectrum of both clinical and policy-related research needs in a way that generates maximum benefit for patients.

# 5 Appendix 1 – Areas for research identified by NHS England

**Table 1: NHS England Areas for Research May 2018 – Urgent and Emergency Care, Diabetes, Cancer, Mental Health, Primary Care, Nursing and Medical Directorate's**

This table presents the areas of research identified by NHS England that the NIHR have categorised into A and B, although this allocation may change as assessment progresses:

**A.** Areas NIHR are already taking forward, for example: already advertising against this area, under review by prioritisation committees, research brief already in development/advertised (TOTAL OF 15)
**B.** Some evidence exists or being addressed through current NIHR research (TOTAL OF 16)

There are 31 areas for research that have been categorised into A and B, although a number of areas include multiple questions/issues. Those areas that fell into category C will be reviewed and further developed in accordance with the NHS Long-Term Plan.

Research needs which overlap with James Lind Alliance Priority Setting Partnership (JLA PSP) priorities are highlighted with a **, and the relevant question from the JLA PSP is included alongside NHS England's statement of research need.

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| **Areas NIHR are already taking forward, for example through already advertising against this area, under review by prioritisation committees, research brief already in development/advertised (TOTAL OF 15)** | | |
| Mental Health 01 | Depression in over-65s | What is the rate of **untreated depression in over-65s on general medical wards**: what is an appropriate intervention and what is the associated impact on resource utilisation and mental and physical health outcomes? |
| Mental Health 02 | Integration of physical and mental health | **Emerging models from STPs/ACOs/ICSs that are integrating physical and mental health**. Assessment of different pathways within these emerging models including: children and young people, adults, older people, frailty, dementia:<br>• What are the most effective service models, staff mix, staff skills and competencies and what are |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| | | the implications for service users?<br>• What particular mechanisms are associated with cost-effective delivery?<br>• What are the key barriers and facilitators to effective implementation? |
| **Mental Health 03 | Children and young people | **Children and young people with insulin-dependent diabetes and anorexia:** To be informed by the forthcoming report of an overview of systematic reviews and meta-analyses on CBT.<br><br>**JLA:<br>• *What are the cognitive and psychological effects of living with type 1 diabetes?* |
| Mental Health 04 | IAPT | What is the **long-term durability of clinical gains in IAPT (improving access to psychological therapy)**, and is this affected by the use of medication?<br>This may include primary research with existing IAPT interventions and the introduction of follow-up care. |
| Mental Health 05 | Early intervention in psychosis | What is the **clinical and cost-effectiveness of continued treatment, including treatment of psychosis prodrome (ARMS), in early intervention in psychosis (EIP) compared to usual care** (discharge at 3 years) on relapse rate, suicidal behaviours, symptoms |
| Primary Care 01 | Primary care networks | **Primary care networks:**<br><br>• Which are the most effective collaborative delivery models of primary care to best manage demand across the system and improve patient outcomes, and what are their impacts on costs in the health and care system?<br>• What are the barriers and facilitators to ensuring successful outcomes when bringing multiple GP surgeries and other primary care providers together across a large geographical location? In particular, what role do financial incentives play in this?<br>• Why are certain networks more effective than others and what interventions can be implemented to improve outcomes? |
| **Primary Care 02 | Digital tools | **Use of digital tools within primary care:** |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| | | • What is the actual and potential impact of new automated (AI) symptom checking and sign-posting, and new consultation channels and models e.g. video and online consultation, upon patient outcomes, and primary care workload? How does this vary for digitally activated and non-activated patient groups?<br>• What are the most effective automated systems management approaches which result in high-levels of GP engagement? What are effective methods of presenting data that support changes in primary care practice?<br>• What are the barriers and motivators to using digital technology among primary care practitioners?<br><br>**JLA:<br>• *How can GP practices appointment systems (e.g. telephone, online) be improved?* |
| Urgent & Emergency Care 01 | Digital tools | **Is digital 111 clinically safe, effective and efficient** at triaging and streaming patients? What is the relative clinical safety and efficacy of streaming patients via digital 111 and telephone 111? |
| Diabetes 01 | Digital tools – diabetes prevention | **Evaluation of Digital Technologies in diabetes prevention**<br><br>• How far can you digitise an existing face-to-face lifestyle programme for diabetes prevention and assume that the benefits will continue to flow for patients? Within this RCT, it may be possible to test the effectiveness of different evaluation approaches by carrying out studies within a trial (SWAT).<br>• The effectiveness of digital diabetes prevention apps in supporting weight loss in people with a high BMI |
| **Diabetes 02 | Digital tools – diabetes management | **Evaluation of Digital Technologies in diabetes management**<br><br>• What is the clinical and cost-effectiveness of new technologies developed to assist the monitoring and management of diabetes? And in which patient groups are they most effective?<br><br>**JLA:<br>• *What is the best way to encourage people with type 2 diabetes, whoever they are and wherever they live, to self-manage their condition, and how should it be delivered?* |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| | | • *How can people with type 2 diabetes be supported to make lifestyle changes to help them to manage their condition, how effective are these lifestyle changes, and what stops them from working?*<br>• *How can healthcare professionals be supported to deliver better care for people with Type 2 diabetes?* |
| **Diabetes 03 | Prescribing | **Do general practices that prescribe high-cost diabetes drug therapies have better patient outcomes** (according to the National Diabetes Audit, NDA) than practices that prescribe lower-cost therapies? *This question would need to be nuanced around case mix matching; and could be a fairly broad commissioning brief asking for studies using routine data (not primary research).*<br><br>OR: **Do practices with good National Diabetes Audit (NDA) outcomes have higher-cost prescribing practices compared to practices with poorer outcomes?** This question would need to be nuanced around case mix matching; and could be a fairly broad commissioning brief asking for studies using routine data (not primary research).<br><br>Additional research on specific areas such as: intensification of therapy, de-escalation, drug combinations and timeframes and the added benefits in specific patient cohorts (under 50s, frail elderly, dementia, severely obese with associated complications) would also be beneficial. |
| **Medical 01 | Autism | The **effectiveness of current NHS services for people with autism, particularly where autistic people are disproportionately over-represented**. These include **epilepsy treatments, eating disorder treatments, depression treatments** and physical health treatment in general practice. What adaptions to services would improve their effectiveness?<br><br>**JLA:<br>• *Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people?*<br>• *How should service delivery for autistic people be improved and adapted in order to meet their needs?* |
| **Medical 02 | Risk stratification | Is there a **valid population risk stratification tool** using existing NHS health deficit data which permits accurate population sub-stratification to predict health and social care utilisation risks and key health |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| | | outcomes including mortality for all adults?<br><br>**JLA:<br>• *Is there a correlation between poor outcomes in older people with multiple conditions and inadequate levels of care received by them?*<br>• *How can the recognition and management of frailty be improved in older people with multiple conditions? Would this lead to an increase in perceived quality of life?* |
| Medical 03 | Older people | Are there cost effective **wearable technologies capable of detecting adult human frailty** which predict risk of onset, permit reliable diagnosis of frailty by degree and are capable of tracking frailty progression over time? |
| Medical 04 | Stroke | **Thrombectomy after stroke: optimal configuration of stroke services** (in terms of delivering clinical outcomes and cost-effective care) to enable uptake and dissemination of this new treatment |
| **Some evidence exists or being addressed through current NIHR research (TOTAL OF 16)** | | |
| Cancer 01 | Early diagnosis, best targeting and risk stratification | **Use of Faecal Immunochemical Test (FIT) in primary care**. To improve the sensitivity and specificity of models and assess the health economics in short term and long term within the following categories of use:<br>i. As a screening tool<br>ii. In symptomatic populations<br>iii. In patients with polyps to support stratified follow up |
| Diabetes 04 | Type 2 Diabetes | **Interventions in the under 40s with type 2 diabetes** |
| Diabetes 05 | Obesity | Clinical and cost-effectiveness of **individualised interventions for children with obesity** |
| Diabetes 06 | Obesity | **Clinical management of obesity**, including the effectiveness of tier 3 weight management services and return on investment for bariatric surgery |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| Medical 05 | Obesity | **Effective interventions for weight loss for children and families.** |
| **Medical 06 | End of Life | 1. **Early identification of people likely to be in their last year of life and impact on improved outcomes**<br>2. **Application of NHSE's comprehensive model of personalised care to the end of life**<br>3. Effectiveness and cost-effectiveness of different service models for addressing **unscheduled urgent needs for people in their last year of life** – including within emergency departments, rapid response services, 24 hour helpline, hospice at home, etc.<br><br>**JLA:<br>• *Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?*<br>• *How can we achieve excellence in delivering end of life care in the Emergency Department; from the recognition that a patient is dying, through symptomatic palliative treatment, potentially using a dedicated member of staff to work with palliative patients and their relatives, and handling associated bereavement issues?*<br>• *What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.*<br>• *What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?* |
| Medical 07 | Older people | What are the **most effective health interventions to prevent onset or progression of lost intrinsic capacity (frailty)** in adults? |
| **Medical 08 | Clinical effectiveness/ safety | **Rapid and accurate diagnosis of serious infections including sepsis**.<br><br>**JLA:<br>• *Do early undifferentiated (broad spectrum) antibiotics in suspected severe sepsis have a greater benefit and cause less harm to patients than delayed focused antibiotics in the Emergency Department?*<br>• *In adult patients with presumed sepsis in the prehospital environment does the administration of* |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| | | *prehospital antibiotics compared to no antibiotics decrease mortality?* |
| Medical 09 | Stroke | How does **peer support improve outcomes in stroke and other long term conditions**? |
| Medical 10 | Clinical leadership | A systematic review on **evaluation methodologies for clinical leadership programmes** |
| Medical 11 | Dental | **Impact of deterioration in oral health on other health outcomes** (e.g. e.g. diabetes, cancer, heart disease, non-communicable diseases, multi-morbidity and deterioration on multiple organ systems through a cumulative inflammatory burden). |
| **Nursing 01 | Maternity | **Most effective and cost-effective interventions to reduce pre-term birth.**<br><br>**JLA**:** *Which interventions are most effective to predict or prevent preterm birth?* |
| Nursing 02 | Maternity | **Population preferences regarding place of birth and the costs of births in different settings** (obstetric-led units, freestanding midwifery units or at home) to ensure appropriate planning of birth services within STPs. |
| Nursing 03 | Maternity | **The benefits of continuity of care from a midwife, or team of midwives, during pregnancy** for different cohorts of women (e.g. those with complex medical or social needs)**.** |
| **Nursing 04 | Children and Young people | **Children and Young People (CYP) with either a Learning Disability, Autism or both**:<br><br>- Which groups experience crisis that results in hospital/residential school/care, why and what can be done to address this?<br>- What are the barriers to and enablers of positive care, particularly up-stream (primary care, early intervention, upskilling families/cares) and what can be done to address them?<br>- Evaluation of existing service models, specifically through children's lens<br>- Issues with system leadership and what can be done to improve it?<br><br>**JLA: |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| | | • *What is the impact of adolescence on autism? And what support is effective in helping autistic adolescents into adulthood?*<br>• *What training do school and nursery teachers need to achieve the best possible experiences/outcomes/employment prospects for children with autism and/or identify the early signs of autism?* |
| Nursing 05 | Children and young people | The **effectiveness and take up of positive behaviour support** across ages, all settings, home, school, care provider, hospital, care home etc. |

**Table 2: NHS England Areas for Research May 2018 – Specialised Commissioning**

This table presents the areas of research identified by NHS England Specialised Commissioning that the NIHR have categorised into A and B, although this allocation may change as assessment progresses:

- **A.** Areas NIHR are already taking forward, for example: already advertising against this area, under review by prioritisation committees, research brief already in development/advertised (TOTAL OF 3)
- **B.** Some evidence exists or being addressed through current NIHR research (TOTAL OF 8)

There are 11 areas for research that have been categorised into A and B, although a number of areas include multiple questions/issues. Those areas that fell into category C will be reviewed and further developed in accordance with the NHS Long-Term Plan.

Research needs which overlap with James Lind Alliance Priority Setting Partnership (JLA PSP) priorities are highlighted with a **, and the relevant question from the JLA PSP is included alongside NHS England's research need.

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| **Areas NIHR are already taking forward, for example through already advertising against this area, under review by prioritisation committees, research brief already in development/advertised (TOTAL OF 3)** | | |
| Spec Comm 01 | Mental Health Category 1 | Impact of **early intervention parenting in deaf children** on quality of life, mental health and neurodevelopmental milestones |
| Spec Comm 02 | Mental Health Category 2 | Analysis of **patient-staff interactions in adolescent psychiatric units** and relation to outcome |
| Spec Comm 03 | Trauma Category 1 | **Radiofrequency denervation for low back pain of facet joint origin** |
| **Some evidence exists or being addressed through current NIHR research (TOTAL OF 8)** | | |
| Spec Comm 04 | Internal Medicine | **Exercise training (pulmonary rehabilitation) in pulmonary hypertension** |

| Group/# | Specific Area/Category | Topic |
|---|---|---|
| | Category 1 | |
| Spec Comm 05 | Internal Medicine Category 1 | **Transjugular intrahepatic portosystemic shunt (TIPS) for variceal haemorrhage** |
| Spec Comm 06 | Internal Medicine Category 1 | **Rituxumab and intravenous immunoglobulin in the treatment of idiopathic inflammatory myopathy** |
| Spec Comm 07 | Internal Medicine Category 2 | **Adrenal surgery for adrenal incidentaloma** (medical therapy to reduce cortisol) |
| Spec Comm 08 | Internal Medicine Category 2 | Outcomes (mortality, readmissions, Patient rated outcome measures (PROMs)) following **transcatheter aortic valve implantation (TAVI) for aortic stenosis** |
| Spec Comm 09 | Trauma Category 1 | **High frequency spinal cord stimulation for adults with chronic neuropathic pain or failed back surgery syndrome** |
| Spec Comm 10 | Trauma Category 1 | **Hyperbaric oxygen therapy for diabetic foot wounds** that do not respond to standard care |
| **Spec Comm 11 | Women and Children Category 2 | A comparison of **human milk diet with and without bovine milk fortifier on outcomes for preterm infants below 29 completed weeks gestation**<br><br>**JLA:<br>• *What is the optimum milk feeding strategy and guidance (including quantity and speed of feeding and use of donor and formula milk) for the best long-term outcomes of premature babies?* |

**Note:** there were a number of additional questions identified by Specialised Commissioning that were ranked by NHS England as low priority that have not been included in this table.