Creating a healthier Hull

NHS
Hull Clinical Commissioning Group

Research & Development

Hull CCG Annual Report

2016 - 17

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Introduction

The purpose of this Research and Development (R&D) Annual Report is to present information to the Committee on the full year R&D activity for 2016-17. The report provides the evidence that Hull CCG maintains and develops the mandate of 'promoting research, innovation and the use of research evidence' (Health and Social Care Act, 2012).

The report presents information on the following:

- Research-based activity and funding allocations
- National changes in R&D
- R&D strategic work
- Promotion of research evidence and the use of research
- R&D development work for 2017-18

Background

The UK government has stated its firm commitment to promote research throughout the NHS which it sees as essential to continually improve effectiveness of health services and patient outcomes. Indeed, there is an expectation that the UK will be the first research-led health service in the world.

A number of current policy documents have placed a strong emphasis on research activity in the NHS:

- The NHS Constitution 2015 (DoH, 2015)
  One of these principles includes a commitment to 'the promotion and conduct of research to improve the current and future health and care of the population'.

- The NHS White Paper, Equity and Excellence: Liberating the NHS
  'The government is committed to the promotion and conduct of research as a core NHS role. Research is vital in providing the new knowledge needed to improve health outcomes and reduce inequalities'. (DoH, 2010, p.24)

- The government response to the NHS Future Forum report made the following commitments with respect to CCGs and research:
  '*CCG's legal duties should reflect their key role in making sure that, at a local level, the need for good research, innovation and a strong evidence for clinical decisions is paramount*'. (DoH, 2011, p.26)

This mandate is recognised within the latest NHS Planning Guidance 2016/17 – 2020/21 which raises the issue of how commissioners can support research, innovation and growth by building on the research infrastructure which can be a pathway to generate new innovative approaches to service development that impact on service delivery and improve patient outcomes.

1. Research-based Activity and Funding Allocations for 2016-17

1.1 NIHR Portfolio Study Activity (Non-funded by Hull CCG)

The data from the NIHR portfolio study report presents the study activity from April 2016 to February 2017. The report in **Appendix 1** lists the number of studies, number of patients recruited and the number of practices recruiting.

There has been recognition that across the Yorkshire and Humber region, Hull included, that there has been a continued noted reduction in the number of participants recruited into NIHR primary care studies. This reduction has been compounded by the number of national infrastructure changes in the R&D landscape and is not just local to Hull but has been recognised at a national level. The issue was further highlighted at the Hull R&D Steering Group in November 2016 when the Deputy Chief Operating Officer/Senior Delivery Manager (Division Five) from the Yorkshire and Humber Clinical Research Network attended the meeting. It was noted that nationally there was a reduction in NIHR primary care studies and there has not been the high-recruiting NIHR primary care studies as in the previous year(s). To promote NIHR primary care study activity, Hull CCG are aiming to enhance the partnership working with the clinical research network and raise the profile via the Council of Members to inform how GP practices can get more involved in research. The Hull R&D Steering group have been tasked with a number of key actions.

1.2 Non-portfolio Studies Funded by Hull CCG

The reports provide the progress information on the status of studies allocated monies from the Hull CCG R&D budget. Some of the projects pre-date the CCG as they were allocated monies from the legacy days of the PCT, but still come within the monitoring/reporting process of R&D. The data is tabled within the budget years for **2010, (nil activity for 2011-12), 2012-13 and 2013-14.**

1.2.1 Budget Year 2010 – Study Progress Report

Christopher Dalgliesh: The Impact of Socioeconomic Factors on Place of Care and Place of Death	
Purpose	The principal purpose of this study is to investigate whether Socioeconomic Status (SES) is associated with place of death in Kingston- upon-Hull, and if so, to understand some of the contributory factors that may be involved, from the viewpoints of health and social care professionals. Specific objectives are to: • Explore whether there is an association between SES and place of death in Kingston- upon-Hull. • Identify understanding of the effect of SES upon end of life care needs, including any relationship to place of care and place of death, among a range of health and social care practitioners. • Explore the challenges of providing end of life care in the context of lower SES, from the perspective of a range of health and social care professionals. • Generate and explore recommendations for health and social care professionals to improve the experience of end of life care among people of

	lower SES.
Funding	Funded £60,000.00 by NHS Hull as one-off payment to the University of Hull in 2010
Planned activities	The funding for this ended in March 2016. Data analysis is taking place and the work is being written up and submitted as a thesis. The submission of this is expected Spring 2017. The work was presented at the CCG R&D event in April and a report will be prepared for the CCG as a final report (although the larger thesis will also be publically available in due course).
Status	The study is completed. The executive summary and recommendations from the end of study report can be found in **Appendix 2**.
Impact	The outcomes of the study will be shared with colleagues in public health and a Macmillan GP. Once their views are obtained, the CCG will decide how to take this forward.

1.2.2 Budget Year 2012-13 – Study Progress Reports

Professor Simon Rogers and Dr Ian Harvey: Medical Elderly Patient Concerns Inventory (ME-PCI)	
Purpose	The key aim of this research trial is to establish the use of the Patient Concerns Inventory (PCI) as a health needs assessment tool in order to support effective commissioning. The trial will focus on the elderly as a patient group and use the PCI technology to improve the quality of the clinical consultation, and to test whether the technology can be used to identify wider patient needs that can be addressed by CCGs through a combination of direct commissioning, partnership working, and signposting. The trial will establish and validate PCI questionnaires in three areas within DME: neuropsychiatric; gastroenterology; and collapse. It will pilot the usability of each of these three PCIs in a clinical setting on a total of 60 patients. The aggregated data from each clinical area will be used to identify common themes and requirements in order to assess the extent of unmet need. Patients and consultants will be surveyed to assess the degree to which the technology has improved the quality of the clinical consultation.
Funding	£102,661.00 from NHS Hull CCG in 2012
Activities to date	Phase 1 (development of the tool) has completed. Phase 2 (patient recruitment) has been delayed, mainly due to restructuring of the ward. Both patients and consultants report positively regarding the intervention. The consultant team, in agreement with the Chief Investigator, have suggested a one year follow up to identify what services patients actually used, so this can be mapped to their concerns, and used to identify additional services as part of the health needs assessment. This will be provided within the existing budget as a secondary outcome.
Planned activities	The service has identified additional services which access is required to, and this will be formalised when the trial has completed.
Status	The interim end of study report was received in **November 2015.** Writing up stage for the final report due 12 months after the interim report. However the R&D Team have been advised that study team are still awaiting consolidation of peer review. Once consolidated and the chief investigator advises that publication is due the final end of study report will be released.

1.2.3 Budget Year 2013-14 – Study Progress Reports

Tracy Flanagan: A Pilot Feasibility study to examine the use of carers views to inform risk Assessments in Mental Health	
Purpose	The study evaluated the effects of increasing carer involvement in dialogue around risk assessments
Funding	£42,000
Activities to date	Findings attained, end of study report produced
Planned activities	Conclusions attained
Status	The findings have been used to support the implementation of improved carer strategies within Humber NHS Foundation trust inpatient services. Carer and family reception meeting have been standardised and training for Family Inclusive Care Coordination is being delivered to staff. The executive summary can be found in **Appendix 3.**
Impact	Hull CCG feels that the study's results will add support to the involvement of carers and families in the delivery and planning of services. The study will inform future work around risk assessments in mental health.

1.2.4 Budget Year 2015-16 – Study progress Reports

Catriona Jones: Lesbian, Gay, Bisexual and Transgender (LGBT) Experiences of Primary Care in Hull	
Purpose	LGBT individuals face unique health disparities, which are largely unexplored in the population of Hull. It was anticipated that any exploration of the experiences of being LGBT and accessing primary health care in Hull would provide a greater understanding of their experiences in healthcare, identify their specific needs, and facilitate the development of a number of recommendations to address the health disparities and unique health needs of LGBT population in Hull. Our research was designed to explore experiences of LGBT groups in the context of the NHS commitment to equality and fairness, with a view to identifying good practice, and also to highlight areas where improvements could be made. The overall aim of this study was to understand the experiences of those who identify as LGBT when they engage with primary health care services in Hull.
Funding	£30,628.00
Status	Study completed. The executive summary and recommendations from the end of study report can be found in **Appendix 4.**
Impact	The end of study report will be considered by the CCG's Equality Reference Group who will then determine if any further action is required.

Helen Gibson: Factors influencing smoking behaviour in Hull: an in-depth study of local women to understand motivators, attitudes and access to smoking cessation advice and services (FISH)	
Purpose	The overall aim of this study is to understand in greater depth the factors that influence smoking and attitudes and access to smoking cessation services.
Funding	£29937.00
Activities to date	During this period we have secured HRA approval and recruitment is well under way. Recruitment literature (posters and leaflets) has been distributed in 30 local community venues and in GP surgeries. In total over 100 posters and 100 leaflets have been distributed. To date we have conducted interviews with 25 women which means we are over half way to meeting our target recruitment of 40 women. 22 of the interviews have been transcribed and initial analysis of the transcripts has commenced.
Planned activities	On-going recruitment.
Status	Study on-going.
Impact	None yet applicable as study still is continuing.

Dr Sathyapalan: Service Users' Perspectives on Accessing Type 2 Diabetes Mellitus Services within Hull	
Purpose	Primary Objective To determine service users' perspectives around accessing and utilising T2DM Services within Hull Secondary Objectives • To identify which T2DM services are used within Hull and why • Any reasons for not utilising the various T2DM services within Hull • Any barriers service users experience in accessing the various T2DM services within Hull • The ability of service users to frequent the various T2DM services within Hull • How service users value the various T2DM services within Hull • How satisfied service users are with the various T2DM services within Hull • Any suggestions service users have for T2DM service development within Hull • To develop a methodological tool for understanding patient experience of services including accessibility and further identifying areas for improvement of service provision for patients with T2DM in England

Funding	£22,864.00
Activities to date	The stage 1 of the study is almost complete (focus groups and interviews). Stage 2 is well underway and is on trajectory to meet recruitment targets. So far the study has provided information which meets the primary and secondary objectives (as outlined below). After the completion of study it is envisaged that additional information will be provided which further meets the objectives.
Status	Study on-going.
Impact	None yet applicable as study still is continuing.

Jo Bell: Access to mental health services: exploring the barriers and facilitators to helping Hull's distressed young people	
Purpose	This project aims to explore what support is available and how the various stakeholders interact in providing that support. Crucially it also aims to determine what help young people want, what they feel they have available to them and their perceptions of accessing that help. Using an online survey, interviews, and focus groups, this unique 12 month project will focus on the local community and its relationship with services.
Funding	£33856.80
Activities to date	We have successfully: secured institutional and organisational ethical approval for the research project ; appointed a Research Assistant; designed, developed and implemented an online survey for young people; designed, developed and implemented an online survey for parents of young people; established a steering group of young people and held two meetings with this group so far; undertaken in-depth interviews with young people who have experience of accessing mental health services in the local area and parents of young people who have experience of accessing mental health services in the area; undertaken 3 focus groups with professionals who work with young people with mental health difficulties; held regular meetings with the research team to ensure progress. We have started a twitter feed to promote the research and highlight issues around young people's mental health generally in the area.
Planned activities	We are currently on course to achieve our aims by the end of the project in December 2016.
Status	Study completed. The conclusions and recommendations from the end of study report can be found in **Appendix 5.**
Impact	Hull CCG responded to the study's recommendations as follows: 1. Hull CCG feels that a 'Young People's Mental Health Forum' for professionals is a good idea and something that has been highlighted as a need when discussing young people's mental health. Hull CCG will consider how best to approach this. 2. Hull CCG commissioned an online directory of locally accessible services in 2016, with the website being developed and launched jointly with young people in Hull – the website is www.howareyoufeeling.org.uk the website went live in October 2016, and is currently being reviewed and updated 3. The CCG is encouraging all schools in the area to devote some of their web

	space to young people's mental health with the help of HeadStart colleagues in the local authority. This will allow the 'how are you feeling ?'website to be on the homepage and accessed within schools. 4. A lot of work has been done on access to services over the last year, with a big improvement on waiting times to access services – however there is further work to be done to reduce waits further. We have also introduced a single point of access and removed the label 'CAMHS' replacing it with 'Emotional Vulnerability Hub' – this means that young people can access an emotional and mental health service which will respond to their overall need, rather than just a specialist mental health need. The Hub will work collaboratively with other statutory organisations and voluntary sector organisations to deliver a responsive, coordinated response that is based on individual need, and not on thresholds. The hub is currently being operationalised and will be communicated widely in due course. Young people are also renaming the service. 5. Hull CCG and the Local Authority have jointly developed a workforce development plan which is currently being reviewed and refreshed for 17/18 – we will certainly ensure that training and education is available. Hull CCG has commissioned self-harm training which is being rolled our across the workforce from the end of March 2017. Through the HeadStart programme, a lot of education on mental health is being delivered within school settings. Further investigation into how best to support GP's will be undertaken. Much of the research findings will impact on the content within the 'How Are You Feeling?' website and this will be reviewed/amended accordingly. In terms of knowledge around MH and incorporating this into school timetables, the HeadStart team are working closely with schools to review their PSHE polices and this information will be shared. It is noted that young people would prefer to be assessed face to face rather than over the phone, and further exploration around this will need to be done. Also, more information around the language used which young people have picked up on.

1.2.5 Budget year 2015-16: Research Capability Funding Allocation - Study Progress reports

Hull CCG was allocated Research Capability Funding (RCF) for 2015-16 of £20,000.00. The Department of Health (DoH) has defined criteria of how the monies can be spent. Based on the national guidance, a local bidding process was developed and, to aid the decision making process, a support tool developed in partnership with R&D peers from West Yorkshire; see **Appendix 6.**

The bidding process closed in January 2016 and a decision was made before the end of the 2015-16 financial year. Five applications were received and reviewed by the Hull CCG R&D Steering group. Three of the applications were successful. The study progress reports are below.

Ann Hutchinson: RfPB grant for breathlessness study	
Purpose	To support staff costs in order to build a grant for a larger NIHR study around breathlessness.

Funding	£9138.00
Activities to date	I (researcher) have made good progress with the systematic review. As a result of working on this project, I have been invited to collaborate with an international group performing a Cochrane review in a broader but related area. This search covers the area of interest in this study and so I have taken this opportunity. However, this means that the review will be completed a little later than planned and will be completed in February. I have conducted a dissemination workshop in July. I have summarised the feedback from this in preparation for contacting local healthcare professionals on their views on what elements identified in the systematic review findings would be best to include in a breathlessness crisis management plan. I have successfully submitted an ethics application to HYMS REC to obtain permission to interview these healthcare professionals. I plan to perform these interviews by April. I have agreed a timeline for the RfPB application with the HYMS research office for submission in the round starting in April 2017.
Planned activities	After the RCF grant finishes I will continue to be employed by the University of Hull until February 2018 from Alumni funding to work on development of the feasibility study that will be applied for in the RfPB application which is part of the RCF funding aims.
Status	Work on-going.
Impact	None yet applicable as study still is continuing.

Catriona Jones: Non-attendance and attendance in perinatal mental health care	
Purpose	To inform a larger study aimed at exploring the experiences of women with perinatal mental health problems.
Funding	£5682.00
Activities to date	During this 18-month period, a total of 76 women (58 from Hull) did not attend the first appointment with the specialist team; all of these women are included in the analysis. Referral forms were also examined for 63 women who did attend (35 from Hull). Data were transferred from Microsoft Excel to SPSS (version 24); where relevant, variables were coded to facilitate analysis. Descriptive analyses were carried out and data presented in graphs and tables as appropriate. Significant differences between attenders and non-attenders were analysed using Chi-Square Tests and Fisher's Exact Tests where necessary for categorical variables and independent t-tests for continuous variables.
Planned activities	We will discuss these findings with members of the specialist perinatal mental health team with the aim of interpreting results and drawing up a plan for further actions and research.

Status	Study completed. The conclusions from the end of study report can be found in **Appendix 7.**
Impact	Dialogue via the R&D team has taken place with the study lead and the designated commissioning manager from Hull CCG. The findings have been taken to the Perinatal Mental Health Team in Hull and, as a result, potential changes to practice are being explored. To further the local impact of the study beyond the Maternity Services forum other options are being explored of presenting to wider forum(s) with the designated commissioning manager at the CCG. So the local impact of the work is still underway.

Jane Wray: Involving Carer's in Risk Assessment in Acute Mental Health Settings	
Purpose	To support the development on an NIHR RfPB bid for a larger study.
Funding	£2781.00
Activities to date	Completed work is prepared for publication (to support the final RfPB bid). This includes 3 papers a) Literature Review b) Carer Contact with Services (Case Notes analysis) and c) reporting of the pilot study (Carer Involvement in Risk Assessment Project). All papers to be submitted for publication by January 2017. We have secured the support of the McPin Foundation to assist with the PPI element of the bid application and on-going support during project delivery in the event of successfully receiving funding http://mcpin.org/ We have recruited two nationally renowned Professors in Mental Health to strengthen the project team and provide on-going expertise and advice (Professor Alan Simpson – City University London and Professor Doug MacInnes – Canterbury Christ Church University)
Planned activities	The primary objective was the preparation of the bid for submission for RfPB monies. This has been drafted up and work is on-going as progression is subject to successful PPI engagement and further feedback from external experts. The development of a PPI group to support the project is still on-going – the project team have engaged with three locally established PPI groups and consumer panels to date to discuss the project and recruit potential carers. Final work required to complete the submission (i.e. in relation to staff time) is being supported by Humber Foundation NHS Trust and the FHSC at the University of Hull.
Status	On-going.
Impact	None yet applicable as study still is continuing.

1.2.6 Funding allocations for 2016-17

The allocation of monies from the R&D Budget for 2016-17 was formalised via an extraordinary meeting held in September 2016. In total **fourteen** applications were received but only **two** met the

criteria and were reviewed and considered for funding. There was some discussion over the interpretation of the research theme on the round of bids. The table below provides a list of the successful projects:

Principal Applicant	Funding amount	Study Title
Dr Lesley Glover	£29964.00	Working with older people to design sustainable healthy lifestyle interventions
Dr Vincent Mann	£15,270.00	A comparative study of standard care versus a new integrated care pathway in primary care (Hull) for NAFLD patients: Their impact on patient journey, experience and outcomes

2. National changes in R&D

2.1 Excess Treatment Costs New Guidance, Pathway and Procedure

Excess Treatment Costs are the difference between the standard cost of treating the patient and the treatment cost arising out of the patient's participation in a research study.

The NHS in England has a statutory responsibility to promote health and social care research, funded by both commercial and non-commercial organisations (Health and Social Care Act, 2012). Further guidance was issued by NHS England in November 2015 that stipulates the basis for attributing the costs of health and social care research including Excess Treatment Costs for non-commercial research. This sets out that Excess Treatment Costs are to be funded through the normal commissioning arrangements and identifies what principles of good practice can underpin the management and administration of Excess Treatment Costs.

The Department of Health mandate requires that the NHS:

"--- ensure that the new commissioning system promotes and supports participation by NHS organisations and NHS patients in research funded by both commercial and non-commercial organisations". (NHS England, 2015)

The costs of research have to be identified and funded and the NHS responsibility extends to ensuring that the treatment costs, including Excess Treatment Costs (ETCs) of patients involved in non-commercial research are met.

The responsibility for meeting patient care costs, resulting from research and development, was set out in 'HSG (97)32' (AMRC, 2013a)

One of the Key recommendations from the Association of Medical Research Charities (AMRC) for commissioners is:

- Develop a process and earmark a recurring budget to ensure excess treatment costs are managed without causing delays to research. (AMRC, 2013b)

The North Yorkshire and Humber R&D service have established a local process in collaboration with the CCG R&D Steering Group and finance team, to log and identify the agreed spend on Excess Treatment Costs (ETCs).

The number of ETCs that were funded by the CCG for the 2016/17 financial year are listed below:

Study Title	Study details	ETC Amount Approved	Date Approved
BASIL III	The study is based at HEY and is investigating the efficacy of treatments for severe Ischaemia of the Leg. The principal research objective is to determine which of these methods – plain balloon, drug-coated balloon or drug releasing stent – keeps the patient alive and with their leg intact, the longest. The ETC will cover the use of drug eluting stents/balloons to patients.	£5,025.00	12/12/2016
ALLHEART	This is a clinical trial that will be aiming to recruit across the GP practices in the Hull CCG area. It has potentially wide-ranging benefits in terms of a prospective reduction in reducing risk of strokes, heart attacks or dying due to cardiovascular disease for ischaemic heart disease patients. Specifically, the ETC is to cover the cost of allopurinol within the trial.	£877.50	16/02/2017

3. Establishment of R&D Guidance

3.1 Criteria for Funding Research Projects in 2016/17

The theme agreed was to commission research on *'Integration and new models of care'* this aimed to provide input into the innovative Hull 2020 programme of work. Examples of research questions included:

- How can integration be defined and how can roles and skills be enhanced across several organisations to provide greater impact and clarity for service users/patients on service delivery?

- What can we do to give patients the knowledge and skills to have the confidence to manage their own health?
- What models of care can be built around the individual?
- How do models of care in Hull compare with other similar geographic areas?
- What are the barriers, professional, organisational and patient to integration?
- What needs to be in place for service delivery to work for service users/patients in Hull?

As per the agreed pathway and procedure the process was centrally coordinated by the North Yorkshire and Humber R&D service.

Point **1.2.6** refers to the outcome from the applications received in 2016/17.

4. R&D Strategy 2014-17

The establishment of an R&D strategy was formally agreed by the Board in 2014. This sets out the key objectives for Hull CCG and is reflective of the Hull 2020 vision. The strategy is being operationalised through the R&D Steering group which reports in to the Planning and Commissioning committee and the Quality and Performance committee. Proposed next steps to review the strategy are currently under consideration. The strategy is underpinned by a strategic R&D Action plan.

4.1 R&D Action Plan

The performance R&D Action plan sets out the key objectives identified in the R&D Strategy and its progress is monitored through the R&D Steering Group. The action plan has been revised to reflect the evolving nature and growth of the R&D agenda; this is shown in **Appendix 8.**

5. Promotion of Research Evidence and Use of Research

5.1 Research and Development Steering Group

In recognition of the national agenda to offer a firm commitment to the promotion of research, innovation and best evidence-based practice, a Hull CCG R&D Steering Group has been established. The Terms of Reference have been agreed. The purpose of the group includes the following areas:

- The CCG promotes opportunities for high-quality and relevant research
- Good research leads to innovation and provides a strong evidence base for clinical decision making
- The promotion and conduct of research is embedded in Hull CCG
- A developing and evolving knowledge base is established to improve health outcomes and reduce inequalities

Meetings of the R&D Steering Group are held bi-monthly and the minutes from the meetings are disseminated to the necessary committees that R&D report to.

There is proactive dialogue with partners within Public Health to further the level of engagement and potential collaboration on projects that the CCG are receiving requests on to financially support. The level of engagement has been reflected in the Action Plan for 2016-17 **(Appendix 8).**

6. Development Work 2016-17

6.1 Applications for Financial Support of Research Projects 2016-17

Calls for applications for financial support of research projects for 2016/17 financial year were managed by the North Yorkshire and Humber R&D Service. The calls for applications were on the theme of 'integration and new models of care' as outlined in **3.1**

7 Development Work for 2017- 18

7.1 Academic Arrangements with Hull, York Medical School (HYMS)

On-going work during 2016/17 has produced strengthening relationships with Hull, York Medical School (HYMS). These close links are to be enhanced in the further development work that will be taking place with the Dean of HYMS and the recently announced investment from the Yorkshire Cancer Research Charity. Alongside this HYMS are appointing a new Professor of Primary Care Research who will be establishing links with the CCG and the R & D Steering group. Potentially the Yorkshire Cancer Research monies which are further outlined in **7.3** will bring exciting new research investment to the local population in Hull.

7.2 Prospective Work on Utilisation of R&D Spend

A review of the current bids application is due to be undertaken by the R&D Steering group, engaging with other stakeholders, to explore wider opportunities in the utilisation the R&D monies in 2017-18 and against the Sustainability and Transformation Plan footprint (STP).

7.3 Yorkshire Cancer Research Investment – Monies for Hull

Investment has been attained from the Yorkshire Cancer Research to develop initiatives in Hull that will improve lung cancer outcomes and increase early diagnosis. The charity will invest in two Hull Initiatives. Firstly, the Dean of Hull, York Medical School (Professor Una Macleod) will raise awareness of symptoms and encourage smokers and ex-smokers to attend lung health checks. Her team will work with GP practices in the area to make it easier for people to get appointments and referrals for chest x-rays if they experience potential lung cancer symptoms. Secondly, Dr Lesley McGregor and Dr Christian von Wagner, based at University College London, will aim to increase participation in bowel scope screening by developing a leaflet and by comparing different types of

GP reminders for people who fail to attend their appointment. This will enable them to see which works best.

7.4 R&D Evidence-informed Commissioning Baseline Survey

The North Yorkshire and Humber R&D team are undertaking an evidence-informed commissioning baseline survey to establish locally what understanding NHS commissioners have of using and applying good evidence and research in the decision making process. The survey has been collated in partnership with the Knowledge and Library services at Hull and East Yorkshire Hospitals Trust. The CCG currently have a service level agreement with the library services, the baseline survey will help to inform if there are any gaps in service provision and any training needs that the CCG staff have identified. This will be circulated to CCG Staff at the beginning of March 2017 via 'survey monkey'.

Summary

This report presents evidence that Hull CCG is continually striving to be at the forefront in making the promotion of research and the use of research evidence a part of its core work. The report demonstrates how the outcomes from the research are being translated into making a difference to the needs of the population in Hull and helping to inform commissioning decisions. This has been shown, for example by demonstrating the outputs from funding local projects and working with partner organisations, including academia, public health and the progressive work of the Hull R&D Steering Group.

The developments in 2017/18 will aim to further promote this commitment and how R&D links into the Sustainability and Transformation Plan. Further evidence will drive forward research, service evaluation and innovation when addressing the healthcare priorities of the population in Hull to ensure commissioning decisions are based on the best available evidence.

Glossary of Terms

R&D	Research and Development
Hull CCG	Hull Clinical Commissioning Group
NHS	National Health Service
NIHR	National Institute for Health Research
PCT	Primary Care Trust
PCI	Patient Concerns Inventory
HYMS	Hull York Medical School
RDS	Research Design Service
REC	Research Ethics Committee
MOU	Memorandum of Understanding
AMRC	Association of Medical Research Charities
SES	Socioeconomic Status
SEDA	Supportive care, Early Diagnosis and Advanced disease
CI	Chief Investigator

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Appendix 1

Hull CCG Local Clinical Research Network NIHR Portfolio Study Report

1. Hull CCG Portfolio Study data 2011-2017

The table below shows the recruitment data for Hull CCG GP surgeries broken down per financial year since 2011 (data for 2016/17 captured from 1 April 2016 – 3 February 2017).

Financial Year (Apr-Mar)	No. of patients recruited	No. of NIHR studies currently open	No of Practices recruiting	% of Practices recruiting
2016-17	35	8	14	28%
2015-16	31	5	10	18%
2014-15	313	9	8	14.04%
2013-14	645	13	15	23%
2012-13	804	29	14	23%
2011-12	581	18	17	27%

2. Hull CCG Research-active GP Practices 2016/17

The table below illustrates the names of the research-active GP practices that have recruited within Hull CCG for 2016/17 as well as the studies and recruitment per practice (data captured from 1 April 2016 – 3 February 2017).

GP Practice	Study Ref	Short Study Title	Recruitment
EAST HULL FAMILY PRACTICE	10470	The United Kingdom Aneurysm Growth Study	1
ST ANDREWS PRACTICE	17071	TIME - Treatment in Morning Versus Evening	1
THE AVENUES MEDICAL CENTRE	32585	A study of common and rare genetic variants associated with thinness.	4
WOLSELEY MEDICAL CENTRE	30395	COMMANDS-02 : An e-consult NAFLD Integrated Care Pathway	2
WOLSELEY MEDICAL CENTRE	10470	The United Kingdom Aneurysm Growth Study	1
DIADEM MEDICAL PRACTICE	30395	COMMANDS-02 : An e-consult NAFLD Integrated Care Pathway	4
THE SPRINGHEAD MEDICAL CENTRE	30395	COMMANDS-02 : An e-consult NAFLD Integrated	4

		Care Pathway	
THE SPRINGHEAD MEDICAL CENTRE	17071	TIME - Treatment in Morning Versus Evening	1
THE SPRINGHEAD MEDICAL CENTRE	20015	PRIM 5039	1
ST ANDREWS PRACTICE	19695	REACT Trial	1
DR GS MALCZEWSKI'S PRACTICE	10470	The United Kingdom Aneurysm Growth Study	1
CHP LTD - SOUTHCOATES	10470	The United Kingdom Aneurysm Growth Study	1
FIELD VIEW SURGERY	10470	The United Kingdom Aneurysm Growth Study	1
JAMES ALEXANDER FAMILY PRACTICE	31408	CADPC-II v1	5
JAMES ALEXANDER FAMILY PRACTICE	17071	TIME - Treatment in Morning Versus Evening	2
LAURBEL SURGERY	10470	The United Kingdom Aneurysm Growth Study	1
NORTHPOINT	10470	The United Kingdom Aneurysm Growth Study	1
HAXBY GROUP HULL	10470	The United Kingdom Aneurysm Growth Study	1
HAXBY GROUP HULL	2848	A coordinated programme for improving the outcome of very early inflammatory arthritis	1
HAXBY GROUP HULL	30395	COMMANDS-02 : An e-consult NAFLD Integrated Care Pathway	1

Appendix 2

Research Project Final Report

A. Project title

The impact of socioeconomic status on place of care and place of death

B. Abstract/Executive summary

Background

People from poorer social classes experience worse care outcomes at the end of life, and are more likely to die in hospital. Although a limited amount of research has been conducted into the perspectives of the healthcare and medical professionals involved in care at the end of life, little has addressed attitudes to social class.

Methods

Eight focus groups with 48 health and medical professionals were conducted in Kingston-upon-Hull, UK. Participants were asked to discuss their impressions of socioeconomic status in relation to delivering care at the end of life, especially with regard to decision making related to places of care and death. Data were analysed using a systematic qualitative method based on the principles of grounded theory.

Results

Three themes emerged:

Communication: The ways in which professionals perceived communication was considered differently (positively and negatively) between different social classes.

Socio-demographic factors: Medical practitioners were more likely than other participants to accept social class as influencing their decision-making. Patients from higher socioeconomic backgrounds were identified as better equipped to express their wishes. However, closer family networks associated with poorer families were seen to offer more support. Practitioners also expressed a greater sense of paternalism towards poorer patients.

Organisation of care and resources: Inequity emerged in narratives regarding inability of patients' relatives to cope at home or with admission to hospital at the end. Practitioners recognised that needs varied according to socioeconomic status and practised tailored care to provide equity. There was a reluctance to discuss this, however.

Conclusions

Practitioners found difficulty in discussing differences of social class, but still tailored their care to patient need. This duality presents challenges for palliative service management.

Recommendations

- A limited understanding of equality (where everybody is treated the same way) and equity (where everybody is given individualised support to achieve at least a minimum level) was evident. Tailoring of care in this way was still conducted, but informally by individual practitioners. This informal nature (and associated issues of limited record keeping) risks inconsistencies across the service, duplication of effort and patients *falling through the cracks.* **Ensuring practitioners are aware of these issues is recommended.**
- An assumption that *richer patients have it better* was common. While it appears to be the case that material wealth is useful in resilience to unplanned change, patients from higher socioeconomic groups were often seen as more socially isolated. Service availability in different communities may also offer challenges. **Practitioner awareness of these challenges may be beneficial.**
- The importance of effective communication between all involved in the end-of-life process was seen as key to achieving preferred outcomes for the dying person, and securing their emotional legacy for family members. **Maintaining effective interpersonal and interprofessional communication and relationships was seen as key for maintaining the patient's legacy, and for supporting family members' future interactions with healthcare (and particularly end-of-life) services.**

Appendix 3

A Pilot Feasibility Study to examine the use of carer views to inform risk assessments in Mental Health

Executive Summary

Background: Involving carers is a key priority in mental health services. Carers feel sharing information regarding 'risks' posed by service users is currently problematic and seldom takes place.

Aims: This study evaluated the effects of increasing carer involvement in dialogue around risk assessment.

Method: Staff-carer risk consensus scores were measured pre/post introduction of a structured dialogue. Carer experience with involvement was surveyed pre-test and compared with the post-test intervention group.

Results: Statistically significant differences were found in carer experience across 4 out of 6 areas of risk. No statistically significant differences were found in relation to staff-carer consensus scores.

Conclusions: Findings provide support for increasing carer contribution to discussions regarding risk. Further work investigating the use of structured approaches to embed carer involvement in clinical practice is warranted.

Appendix 4

Lesbian, Gay, Bisexual and Transgender (LGBT) Experiences of Primary Care in Hull

EXECUTIVE SUMMARY

- This survey included an online questionnaire answered by 78 people, aged from 18-74 (with 12% being over 55) from across the LGBT spectrum in Hull and 3 qualitative focus groups with a total of 13 people from the local LGBT community. They were asked a broad range of questions about their experiences of Primary Care in the City.
- Survey respondents indicated a wide and frequent use of Primary Care services, ranging from GPs, Practice Nurses and Pharmacists to Community Nurses and Community Mental Health Professionals. Most respondents reported accessing services between 2-5 times a year with 26% indicating between 6 and 10 instances per year.
- Overall there were high levels of satisfaction with the care that LGBT people received from Primary Care services and professionals in Hull. The majority of survey respondents felt they always received 'excellent care' from Primary Care professionals and a clear majority felt comfortable in disclosing their LGBT status to a Primary Care professional.
- Of the 39 respondents who had accessed sexual health services in Hull almost 80% felt their sexual health needs had been fully met and the majority of respondents would recommend the service to their friends.
- The majority of the relatively small negative responses within both the survey and focus groups focussed on two issues – 1) Lesbians sometimes felt that they were treated as heterosexual – offered pregnancy test for instance – even after disclosing their sexuality and 2) amongst the small number not comfortable with disclosing their sexuality there was a belief that this could cause a negative reaction.
- Another less positive finding from the survey and focus groups was that transgendered respondents reported that Primary Care professionals often have poor levels of knowledge about transgender issues and the process of gender change.

RECOMMENDATIONS

- Adopting strategies to promote a non-heteronormative healthcare environment for patients may provide LCBT service users with some confidence that disclosure will not be met with judgement. For example, simple steps such as signalling that the organisation is LGBT friendly, providing gay friendly literature/magazines, displaying posters featuring same sex couples, and providing brochures for LGBT support groups may reassure some LGBT patients.
- Having knowledge of the sexual orientation/identity of a service user pre consultation may be a valuable component of the encounter, as it can guide the interactions during the consultation. If a patient has previously self-identified, data suggests it is frustrating to have this disclosure ignored.
- Every healthcare encounter is an opportunity to have a positive effect on the health of a service user. Health professionals, practitioners and all other staff working in primary care

should maximise this potential by learning more about LGBT identities and needs and move towards greater LGBT cultural competency.

Appendix 5

Access to mental health services: Exploring the barriers and facilitators to helping distressed young people in Hull and the East Riding

Taken together our findings suggest a number of important factors for services to embody in improving access to mental health services for young people in Hull and East Riding. Firstly, lack of knowledge and understanding of mental health (including language) can be intimidating for young people. Young people often struggle with the shame and stigma associated with mental health and with emotional literacy. It can leave them scared.

Furthermore, when they speak to adults and make sense of this, there can be mixed results, most notably when adults in schools lack awareness of mental health issues and how to deal with them. This can be a barrier to accessing services. Young people need to feel that there are people they can trust, and be empowered to take steps to access services. This requires the adults in their world to more fully recognise them as service users.

A major reason for many parents/carers not seeking help for their child was that their child did not wish to seek help. So there needs to be: realistic information about the nature of mental health and the nature and purpose of local services that minimises the continuing stigma of having a mental health problem; recognition that it can be the parent who serves as the person coordinating care to the best of their ability so parents/carers need to become informed about their children's specific issues; recognition that young people who lack support from parents/carers, family and peers are a particularly vulnerable group. It is imperative that this group have equal access to services.

To make help seeking easier there needs to be: up to date and widely available information about the options for help that can be used by everyone; recognition that most mental health issues need not go to CAMHS. Our findings indicate that online resources may be a valuable source of information if perceived to be trustworthy and point to the need for: a "one stop" webpage that gives contact details for all local mental health and relevant services and practical ways young people and parents/carers can seek help directly. This information should be in a format that gives young people, parents/carers, school staff and primary care staff more confidence that they can help the young person to find help, despite not having a full understanding of mental health issues. Our findings caution against the use of online resources and applications that offer emotional and mental health support for and young people as a substitute for face-to-face support.

Our findings suggest an important role for schools in Hull and East Riding in supporting young people's mental health. Firstly, there is an urgent need to raise awareness of young people's mental health and developmental disorders amongst staff in schools in Hull and East Riding. Teachers are well placed to identify those who might be vulnerable and in need of support from specialist services. However, there is a limit to what teachers should be expected to provide. Our findings suggest schools working in collaboration with other services, professionals and parents/carers offer best approaches.

For example, young people want education on mental health in schools but our findings suggest best practice would be for this to be delivered by specialist providers (not teachers). Similarly, there is a need for: a dedicated pastoral role in schools (this should be separate from education role, not undertaken by teachers); immediate access to independent counselling services for young people; access to peer support for young people.
20

This research suggests that negotiating appropriate access to support for young people with mental health issues is complex, sensitive, and often a lengthy process. It takes a lot of courage for young people to engage in the first contact with mental health services. Young people tended to need support from an adult or peer even to begin to seek help, and needed someone that they could trust to serve that role. Trust in this sense was synonymous with confidentiality. It also appeared to involve being able to strike a balance between recognising the severity of the young person's distress, and neither minimising nor catastrophising the underlying problems.

The gap between assessment and treatment is an issue in urgent need of attention: quick access to intervention is essential. Best practice according to our respondents would be: initial assessment that is face to face where possible, making sure the first point of contact is friendly, understanding, supportive and confidential; care that is joined up and planned with one professional taking the lead, even when multiple services need be involved; care that fosters open dialogue and trusting working relationships between all parties involved (young people, their parents and carers, and the professionals who work with them). The importance of good relationships in promoting best practice is emphasised across and between all data sets in our study. Relationships are key to improving mental health: good relationships foster trust, confidence, and self-efficacy. Services need to be relationship focused: not just between practitioner and service user, but also between service providers more broadly, to enable ongoing trust and confidence from the population.

Recommendations

1. A Young People's Mental Health Forum needs to be set up for professionals who work with young people to: share practice experiences, knowledge of local services and the most up to date evidence based methods; improve the right skill-mix and promote collaborative working. The professionals' focus groups in our study were a good example of this in action. This forum would require resourcing by the CCG but could be hosted by HEY Mind on Beverley Road, Hull. Quarterly meetings might run at a total cost of around £1500.00 per annum.

2. An online directory of locally accessible services should be established and maintained by the CCG. This would not be expensive but a dedicated member of staff needs to be responsible for updating and maintaining it. It should be a well disseminated, central portal of young people's local mental health services information, including NHS, voluntary and third sector organisations. It will be important that the aforementioned YPMH forum and the directory maintenance team develop a close working relationship so that the directory stays up to date.

3. The CCG should encourage all schools in the area to devote some of their web space to young people's mental health, and this should include a link to the online directory.

4. Young people have difficulty accessing services and require help from trusted adults or peers. Access to services needs to be reviewed, with an emphasis on access being quick, easy and open. Where possible this should reduce red tape and repeated tick box assessments. We recommend that the CCG carry out periodic audits of their mental health services to ascertain whether the thresholds to obtain services are low enough.

5. Awareness raising and training / education for school staff and GPs is required as there is limited understanding of mental health problems and how to approach them in the local context. These groups are often the first to be in contact with young people experiencing difficulties so it is vital they have the knowledge and confidence in their helping responses. We therefore recommend further research to identify gaps in knowledge, understanding and skill-sets amongst these groups followed by targeted intervention.

Appendix 6

RCF Panel aid to decision making

The purpose of the RCF fund is to enable a research orientated culture to develop and be sustained within primary care and foster innovative practice across Hull. All applications should be able to demonstrate where they either:

- Have potential to make a difference to service delivery or patient outcomes if they are a pilot project
  OR
- Enable research activity to continue to grow within Primary Care in Hull

The panel member should consider the following scoring matrix to determine the strength of the application. This is intended to be used as an indicative tool/guide for assessing the applications only.

Rating	**Score**	**Definition**
Unacceptable	0	Inadequate Response
Weak	1	Limited potential with weak/vague concepts, very limited potential for success, limited innovation or quality improvement potential, lacking in information
Marginal	2	Interesting concept only partially developed, some potential for effectiveness and success, requires some additional information
Good	3	Interesting concept with an evidence base that would indicate success, would be innovative and lead to quality improvement
Strong	4	Convincing concept, excellent chance of success, strong evidence base that support this, would lead to an innovation/quality improvement

Application reference number:		
Question	Your notes/comments	Score
1. If this application is to support recruitment and retention (bridging funding), is it clear how funding such a		

post would continue to grow research activity within Primary Care in Hull? If this application is for a pilot project, is there a clear process being used to identify and refine the research question?		
2. Are the aims and objectives for the funding clear? Points to consider: • Innovative or novel approach to the issue/gap highlighted • Improves capacity, helping to build critical mass		
3. Does the request for funding help in promoting primary care research? Points to consider: • The potential to address a local unmet need		
4. Is it clear who will participate in the work and how the different roles are assigned?		
5. Is there a clear time frame, set milestones and targets? Points to consider: • Realistic timeline with milestones that can be achieved		
6. Are there clear key outputs envisaged for the end of the award? Points to consider: • Outcomes are defined • Dissemination of outcome/results is planned		
7. Is it clear how the work will be sustainable beyond the RCF award? Points to consider: • Application demonstrates the infrastructure required to continue • Intention of next steps is clear		
	Total	

Appendix 7

Non-attendance and attendance in perinatal mental health care

Conclusions
It is apparent from this analysis that there are some significant differences between attenders and non-attenders, as well as between women from Hull and women from the East Riding.

To summarise, women are significantly more likely not to attend the first appointment if:

- they are from Hull (especially some areas, e.g. HU9),
- they are younger,
- their relationship status is not known or they are not married,
- they are not employed (or their employment status is not known),
- they are affected by 'low mood', current or previous depression,
- they have a history of self-harm and/or suicide attempts,
- they have responded positively to the Whooley questions (in so far as they have been recorded).
- In addition, women are significantly more likely to attend if:
- they are currently suffering from psychosis or psychotic symptoms
- they have experienced a traumatic birth,
- they have bonding and attachment difficulties,
- they have a personality disorder,
- they are currently receive counselling.

Almost half of all women who missed the first appointment were seen eventually by a member of the specialist team. There were some significant differences between women who were and were not seen eventually.

Women are more likely not to be seen eventually if:

- they self-referred,
- they have been offered a home visit (women in Hull only),
- they are younger,
- they had current or previous depression.
- Women were more likely to be seen eventually if:
- they had current psychosis or psychotic symptoms,
- they had bonding or attachment issues.

The reasons for non-attendance are likely to be complex and multifaceted. While some women may feel that they do not need to see the specialist team, others may not attend for other reasons – even though they may benefit from the involvement. These complex reasons are reflected in the data. Further analysis is required to explore possible interactions between variables. We will discuss these findings with members of the specialist perinatal

mental health team with the aim of interpreting results and drawing up a plan for further actions and research.

Appendix 8

Hull CCG R&D Strategic Action Plan 2016-17

RAG rating	
	Completed / On-track within timeframe
	Pending within timeframe
	Not completed / Completed outside of timeframe

	Strategic Objective	Action	Lead	Timeframe	Progress
1	Sustain a Hull CCG Research Champion at Board level who will assist in identifying research topics against the commissioning priorities.	Appoint an accountable officer at Board level with in the CCG responsible for Research and Development. Identify an Operational Lead to champion R&D activity.	CCG Director of Quality and Governance/ Executive Nurse. CCG Clinical Lead	March 2017	closed

	Strategic Objective	Action	Lead	Timeframe	Progress
2	Strengthen and support the culture of evidence based commissioning underpinned by research and clinical effectiveness.	Publicity via CCG Link on website and in CCG newsletter of research activity and development work Evidence informed commissioning baseline survey to be undertaken via R& D team in partnership with Library and Knowledge services at Hull and East Yorkshire Hospitals Trust	CCG Communications team in dialogue with R and D North Yorkshire & Humber service. R and D North Yorkshire and Humber service with HEY Library and Knowledge services	December 2016 March 2017	
		CCG to maintain and grow funding support for research projects which have an impact on needs of local population	Yearly round of calls for funding support, timelines as per introduction of research cycle.	November 2016	Closed
		Testing out of research cycle set against 2020 vision / commissioning priorities. Bidding process for Research Capability Funding (RCF) instigated	R and D Steering group to evaluate testing process. R&D North Yorkshire & Humber Service to facilitate bidding process for RCF research monies	December 2016 August 2016	closed
3	Ensure the inclusion and opportunities for patients to be involved in research through our main providers' contractual requirements.	Review and report current level of research activity in our main providers as a baseline to inform future requirements and through Quality Accounts reports	R&D North Yorkshire & Humber Service	January 2017	closed

	Strategic Objective	Action	Lead	Timeframe	Progress
4	Develop proactive engagement with partners for knowledge transfer, the translation of research into practice and rapid implementation. For example NICE, Public Health Observatories, CLARHC's, AHSN's, The Cochrane Library, local Higher Education Institutions**.**	Establish partnership and links and the necessary networks, to ensure evidence based practice is sound and robust. Refer into R&D Steering group (Link to no 2)	Hull CCG with local partners/stakeholders including academia, public health.	March 2017	On-going
		Dissemination and translation of research findings to inform commissioning priorities /decisions – reporting streams identified.	R and D service reporting links into Quality and Performance Planning and Commissioning,	Six monthly /annual reporting.	On-going
		Hold a local CCG dissemination event for translation of research (completed and ongoing studies)	Facilitated by R and D Steering group members and R and D service.	April 2016	closed
5	Meet the responsibilities to promote and support research including excess treatment costs associated with non-commercial research.	Maintain clear and transparent process/ local CCG pathway adopted for the handling of excess treatment costs. (ETC).	R and D Steering group	December 2016	On-going
		Consultative input on National Guidance/ policy development in respect of ETC	Hull CCG with R and D service linking in with NHS England, the Local Clinical Research Network-Yorkshire and Humber and other stakeholders i.e. R&D National Forum.		
		NHS England ETC Guidance released November 15, next steps to be identified.			

	Strategic Objective	Action	Lead	Timeframe	Progress
6	Support the engagement of patients and public in research both as participants and researchers.	Support the work of the NIHR through its patient and Public involvement strategy and research champion programme. Increase public involvement and engagement in research studies via provider activity (Refer to Objective 3) Develop an interlink with CCG Communications and Engagement strategic work	R and D Steering group and R and D service to act as an enabler To encouraging PPI input working across the Local Clinical Research network – Yorkshire and Humber	December 2016	
7	Continue to support and promote the local research infrastructure, research capacity and recruitment into NIHR portfolio studies with GP Practices with engagement with the local Clinical Research Network (LCRN) and in partnership with North Yorkshire and Humber R&D Service	Partnership arrangements with CRN to be proactively strengthened. Communication channels to be enhanced	Collective response from R&D steering group on strategic approach to objective (7)	March 2017	