Cambridge Institute of Public Health Research Conference

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ABSTRACTS FOR TALKS

REDUCING INEQUALITY THEME
Chair, Professor Theresa Marteau, Director, Behaviour and Health Research Unit

1. Dr Isabel Clare
   Consultant Clinical and Forensic Psychologist, NIHR CLAHRC EoE

The work of community teams for people with intellectual (learning) disabilities: implications for public health

Background: People with the life-long impairments associated with intellectual disability (ID) are at increased risk, compared with their typically developing counterparts, of health inequalities partly consequent upon an enhanced vulnerability to (i) co-morbidities and premature mortality, sometimes linked to the cause of the disability; and (ii) to their health needs not being adequately met by mainstream services. Specialist community locality-based teams (CTs) were established, in part, to address these two types of inequalities but little is known about the health needs that such teams are asked to meet.

Methods: We examined the reasons for referrals to health and LA staff in five locality-based community teams for adults (≥18y) with IDs in a county-wide integrated ID specialist service in the East of England. The community teams in this study comprised NHS health care practitioners and Local Authority care-managers, commissioning social care. Over three months, there were 292 referrals from external sources (caregivers, GPs etc) or between CT NHS and LA staff.

Results: The range of referrals was striking, and included requests relating to the commissioning/revie​w of social care support, mental health and/or behavioural needs, physical health needs, and parenting. In many cases, though the initial referral was for health care or care management, CTs frequently determined that the referral engaged both parts of the team. Importantly, 78% of the referrals related to known individuals.

Conclusions: While there are methodological limitations, the findings suggest (i) that CTs address a wide range of health needs in adults with IDs but this often also involves consideration of social care needs, implying that integrated teams are required; and (ii) that concepts such as ‘pathways’ and ‘throughput’ are unhelpful for a population whose needs, though frequently intermittent, are likely to be life-long. The impact of recent legislation such as the Equality Act 2010 on health inequalities needs to be assessed."
Using epidemiology to address inequalities in policy, an example from dementia research

Impacting on policy is an important outcome from epidemiological research. Knowing about how much of any particular disease or disorder in the population there is provides us with a sense of need for whole populations not just now, but also in the future.

For dementia there is a perceived level of under diagnosis in particularly the older population, and only epidemiological studies can provide a robust insight into the true level of dementia without the biases of who gets referred into which system, from primary care to specialist centres.

We already know from many studies that a substantial proportion of dementia might be related to common risk factors for diseases (such as smoking, diet and physical activity). How changes in these factors over time impacts on total dementia becomes therefore a question not just of scientific interest but major policy interest.

The Cognitive Function and Ageing Studies have provided estimates on the prevalence of dementia across the country using a large epidemiological investigation where all individuals have been assessed for the presence of the dementia syndrome.

We found that the prevalence of dementia had decreased within the general population over time with continuing strong differences between men and women, and still a strong age effect. Dementia was also found to be more common in deprived communities. These findings should help prioritise funding and case finding approaches to areas of the country with the greatest current numbers of people with dementia and also to those areas where risk factors across the lifecourse have profiles that confer higher risk of future dementia.

The role and activities of Healthwatch to reduce health inequalities and encourage integrated care

2015 research findings will be summarised including a survey undertaken locally in targeted groups not represented in IPSOS or GP patients’ surveys, shows concerns re access to services. The ways that information on people’s experience of health and care services is being used strategically will be presented. Opportunities for researchers to work in partnership with Healthwatch Cambridgeshire will be identified.
Using vignettes to understand differences in patient experiences for White British and Pakistani adults in England

Context: In many countries, minority ethnic groups report worse patient experiences than the majority population. In the UK, South Asians report particularly low scores.

Objective: To examine whether Pakistani people rate simulated GP consultations differently than White British people. If these groups rate consultations the same when viewing identical videos, this would increase the likelihood that low scores observed among minority ethnic groups in real surveys reflect real differences in quality of care.

Design: Experimental vignette study. Trained fieldworkers completed Computer-Assisted Personal Interviews with participants, using a standardized script. Participants rated three video-recordings of simulated GP-patient consultations, using five communication items from the GP Patient Survey. Consultations were shown in a random order, selected from a pool of 16. Setting: Output Areas selected according to ethnic and age composition.

Participants: 564 White British and 564 Pakistani adults (half aged 18-54 and half aged over 55), recruited using an in-home face-to-face approach coordinated by a market research agency.

Main outcome: Mean differences in communication score between White British and Pakistani patients were estimated from linear regression.

Results: Pakistani participants, on average, scored consultations 9.8 points higher than White British participants (95% CI 8.0-11.7, p<0.001). When adjusted for age, gender, deprivation, self-rated health, and video, the difference increased to 11.0 points (95% CI 8.5-13.6, p<0.001). There was evidence that the coefficient for ethnicity was moderated by age (p<0.001) and whether the video was scripted to be “good” or “poor” for communication (p<0.001); the largest differences were seen when participants were older (>55) and where communication was scripted to be poor.

Conclusions: We found substantial differences in ratings between Pakistani and White British participants. If we take these findings at face value (Pakistani patients rate the same care higher), we would conclude that their lower scores in national surveys represent genuinely worse care.
GLOBAL PUBLIC HEALTH THEME
Chair, Professor Nigel Unwin, Strategic Lead for Global Public Health, MRC Epidemiology Unit

1. Emma Pitchforth
   Associate Director of the Innovation, Health and Science group, RAND Europe (CCHSR)

Evaluation of the Nigerian Midwives Service Scheme: barriers and facilitators to implementation

Pitchforth E\(^1\), Exley JLR\(^1\), Abubakar I\(^2\), Onwujekwe O\(^3\), Glick P\(^4\), Chari AV\(^4\), Bashir U\(^3\) and Okeke E\(^4\), on behalf of the BORN study team

\(^1\) RAND Europe
\(^2\) Bayero University, Kano, Nigeria
\(^3\) University of Nigeria, Enugu Campus
\(^4\) RAND Corporation
*author for correspondence:

The Nigerian Midwives Service Scheme (MSS) was created in 2009 with the aim of reducing maternal and infant deaths by 60 percent by December 2015. Key features of the MSS include the recruitment and deployment of newly qualified, unemployed and retired midwives to rural health clinics to ensure access to skilled care.

The BORN study\(^1\) aimed to evaluate the effectiveness of the MSS. Outcomes were compared between households in the catchment areas of MSS clinics (n=208) and in the catchment of matched comparison clinics (n=208) in 12 states. A nested qualitative study was conducted in three states around nine clinics which appeared to be having differing success in terms of recruitment/retention and uptake of services.

Though the program successfully increased the supply of midwives in target communities in the short-run, in the long-run this increase was not sustained. Interview findings highlight that there was a failure, at least in part, of the collaborative model underlying the scheme with the different tiers of government failing to consistently fulfill their assigned responsibilities such as payment of salaries and provision of suitable housing. The apparent lack of engagement of policymakers stemmed from the belief that state and local government were excluded from the schemes design.

The MSS is an ambitious human resources project. Our research highlights a number of challenges arising from the design of the scheme and implementation which are likely to limit its success and sustainability. The findings highlight the complexity of increasing access to skilled care in low- and middle-income countries.

*This study has been funded by the International Initiative for Impact Evaluation.*

2. Professor Paul Pharoah
   Cancer Genetic Epidemiology, Department of Public Health and Primary Care

Moderate penetrance ovarian cancer susceptibility genes: the relevance for panel testing

Abstract to follow
Beyond the virus: The psychosocial impacts of the Ebola outbreak on affected individuals and communities

The most recent Ebola Virus Disease epidemic has been the worst in history, with 28,331 estimated total cases, and 11,310 deaths to date (on 23 September 2015). Guinea, Liberia, and Sierra Leone have been disproportionately affected. This short talk, based on our recently accepted paper in the Bulletin of the World Health Organisation, examines the psychosocial consequences of the Ebola epidemic, which are experienced at the individual and community level. The psychosocial impact of the epidemic has resulted in a reduction in quality of life and productivity, the fracturing of the social system, an increased need for health services, public health planning and health systems strengthening. It is essential that the global response to the Ebola epidemic considers the acute and long-term psychosocial needs of individuals and communities, and is committed to sustainable future public health planning and community-based initiatives focused on ‘building back better’.
1. Dr Jackie Buck  
Research Associate, Primary Care Unit - Department of Public Health and Primary Care  

Inequities in a service struggling to meet demand: findings from an evaluation of a Hospice at Home service in Cambridgeshire  

"Background: Most people want to die at home. The Arthur Rank House Hospice in Cambridge re-launched its overnight Hospice at Home service in 2011 to provide home based hospice level care for people in Cambridgeshire in the final two weeks of life. This paper describes part of a mixed-methods evaluation undertaken to evaluate the nature, scope and equity of the service provision.

Methods: A near time case note survey of all patients referred to the Hospice at Home service for one year from September 2012 (n=315). Quantitative data analysed descriptively, qualitative analysed thematically.

Results: Roles of the service were identified: care co-ordination, specialist ‘end of life care’ assessment and advice, ‘holding’ complex patients until hospice beds become available, hands-on nursing care. Demand far outstripped supply. Approximately a third of all episodes of care requested each month were unfulfilled. People referred to the service were predominantly male (55%). 75% had cancer. Only 10-12% of people who died at home locally with diagnoses other than cancer received support from hospice at home. 50-60% of people who died at home locally with cancer were supported by the service.

Discussion: The service provides comprehensive nursing care for people at the end of life enabling them to stay at home to die, however the service is struggling to meet demand. There is potentially huge latent demand. Further research is needed to understand why so few people with diagnoses other than cancer are referred and to identify interventions to make the service more equitable."

Bone Health in Gambian Women: Impact and implications of rural-urban migration and the nutrition transition

Sarah Dalzell1; Landing MA Jarjou2; Ann Prentice1,2; Kate Ward1; Gail R Goldberg1,2
1MRC Human Nutrition Research, Cambridge, UK; 2MRC Keneba, MRC Unit The Gambia

Urbanisation has been associated with the relatively rapid and recent rise in osteoporotic fragility fracture incidence in many countries, with predictions indicating that hip fracture incidence will increase 6-fold in Africa and Asia by 2050.

Evidence suggests that the nutrition transition is likely to be a key contributory factor. The Gambia is a West African country in nutritional, demographic and epidemiological transition. Over 50% of Gambian people now reside in urban areas; many having internally migrated from rural areas. The aim of this observational study is to explore the impact of rural-urban migration on bone phenotype and lifestyle variables likely to affect bone health.

Hypothesis: Similar groups of rural and urban women will differ with respect to:
Bone phenotype: assessed by dual energy x-ray absorptiometry (DXA) and peripheral quantitative CT (pQCT)
Other characteristics e.g. nutrient intakes, dietary patterns, physical activity and occupation, vitamin D status and body composition

Data collection was conducted from November 2014 – August 2015 at MRC sites in Keneba (rural area) and Fajara (urban area) in The Gambia in two groups of premenopausal women age 35-50 years. The women were either known to have lived in the rural West Kiang district of The Gambia their whole lives; (n=61) or were known to have migrated from west Kiang to the urban coastal areas of The Gambia (n=61) when aged >15 and lived >7 years there. Data and sample collection included DXA and pQCT measures, 2-day weighed dietary intakes, overnight fasted blood sample, 24 hour urine sample, and questionnaires.

This study will provide new information to better understand how important the nutrition transition in The Gambia is to bone health.

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Local intelligent working: the Public Health England Intelligent Working Award East

Background and aims: Robust health intelligence should underpin decision making in health and health care. Considerable effort is now spent developing health intelligence resources which are intended to support local support decision-making. Evidence on how effective these resources are in influencing local policy or practice can be difficult to obtain.

Method: In 2014, local partners working in the East of England were invited to submit entries to the pilot Intelligence Working Award (IWA) are using a standard template. The aims were to gain feedback on how Public Health England (PHE) health intelligence resources had been used and to celebrate local good practice in the use of population health data.

Results: Sixteen entries were submitted and were judged against criteria. Across the 16 entries, 22 PHE health intelligence resources were cited from 11 organisations (10 local authorities and one NHS organisation). Some resources were cited by more than one entry and in total, there were 51 reports of the use of PHE resources. The PHE resources had been used to support a variety of local work including: setting priorities, targeting interventions, performance monitoring, service re-procurement, service improvement, and securing additional funding. When surveyed, 71% of those eligible to enter reported that they would be likely or highly likely to enter if it were re-run. Entrants to the IWA agreed or strongly agreed that IWA is a useful means of sharing good practice.

Conclusion: Award schemes can be a useful way of gathering feedback as well as celebrating good practice.
Enabling patient-centred care in advanced COPD: identifying care and support needs

"The problem: Chronic obstructive pulmonary disease (COPD) is a chronic progressive condition with high symptom-burden, accounting for one death every 20 minutes in England and Wales. Patient-centred care takes into account patient needs and preference but we lack fundamental research on care needs in advanced non-malignant disease and tools to identify them in clinical practice, to enable this. This paper describes unmet care needs of patients with advanced COPD and potential ways to identify needs to enable patient-centred care.

The approach: Mixed-method interviews with a population-based cohort of patients with advanced COPD recruited to the Living with Breathlessness study, their informal carers and key clinicians. Quantitative data include validated patient measures of function, need and service use analysed using descriptive statistics. Purposively sampled multiple-perspective qualitative data on needs and experiences of care analysed using a framework approach.

Findings: 235 patients were recruited: mean age 71.6 years (SD 10.3), 61% male, mean MMRC dyspnoea scale 3.68 (SD 1.04), mean CAT score 23.4 (SD 7.5). Patients identified symptoms they had not reported to clinicians and unmet needs for support with practical tasks, personal care, psychological support and information. Patients’ ability to spontaneously articulate need was limited. Service contacts were predominantly in primary care. Descriptions of primary and secondary care contacts could be characterised as predominantly reactive. When asked about the quality of care some responded with “what care?”: the “care” element of service contacts was invisible to some. Service contacts appeared to be driven by organisational and medical agendas rather than patient-centred.

Consequences: Shifting the focus of care beyond organisational and medical agendas in advanced COPD to a more patient-centred approach requires the proactive identification of need, prompted by clinicians. This could be facilitated by a brief structured holistic tool, grounded in patient data, yet feasible for use in clinical practice."
Are patient self-reports of anxiety and depression reliable indicators of clinical conditions in advanced COPD?

"Background: COPD is a common health problem. Anxiety and depression are common in Chronic Obstructive Pulmonary Disease (COPD) and increase with its severity. Presence of anxiety/depression in COPD is associated with a number of poorer health outcomes. If patients could self-report anxiety/depression, clinical management could be instigated to potentially ameliorate effects.

Aim: To identify whether patients with advanced COPD can self-report anxiety and depression.

Methods: A population-based sample of 216 patients with advanced COPD answered self-report questions on how much they were bothered by anxiety/depression and completed the Hospital Anxiety and Depression Scale (HADS) to screen for anxiety/depression. Analyses first explored the association between self-reported anxiety/depression (‘Not at all’, ‘A little’, ‘Quite a bit’ or ‘Very much’) and a four-level categorization of HADS scores: normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). Secondly, we used binary categorization of both self-report and HADS to calculate sensitivity and specificity: the HADS cut-off of 11 (for probable clinical disorder or “caseness”) and any self-report (‘A little’ to ‘Very much’) to define anxiety/depression.

Results: We found a positive association between the degree of self-reported anxiety/depression and HADS score (p<0.001 for both anxiety and depression). We found sensitivities of 85.2% and 77.8% and specificities of 56.2% and 57.9% for anxiety and depression, respectively. The majority of patients correctly identified their status (64.5% for anxiety and 60.4% for depression).

Conclusion: Patient self-report of anxiety/depression is positively associated with HADS scores. Routinely asking patients with advanced COPD if they are bothered by anxiety or depression may be a useful screening question to highlight those with clinical conditions. Patients with advanced COPD who self-report anxiety/depression may be clinical cases who could benefit from treatment."
6. **Dr Jane Fleming**  
Senior Research Associate, Cambridge Institute of Public Health

**The Oldest Old in the Last Year of Life: Population-Based Findings from Cambridge City over-75s Cohort Study Participants Aged 85 and Older at Death**

Jane Fleming, Jun Zhao, Morag Farquhar, Ann Louise Kinmonth, Carol Brayne, Stephen Barclay, and for the Cambridge City over-75s Cohort Study Collaboration

Aims: To characterize people of advanced old age in their last year of life and compare those dying in their late 80s with those dying aged 90 and older to inform policy and planning.

Study design: Retrospective analysis of prospectively collected population-based data from the Cambridge City over-75s Cohort (CC75C) Study, United Kingdom

Participants: Men and women aged 85 and older at death who died less than 1 year after taking part in any CC75C survey (n=321).

Measurements: Physical health, functional disability, self-rated health, cognitive status

Results: Functional and cognitive impairments were markedly higher for those who died aged 90 and older - predominantly women - than for those who died aged 85 to 89. At least half (49.4–93.6%) of subjects aged 90 and older needed maximum assistance in virtually every daily activity; those aged 85 to 89 needed this only for shopping and laundry. Disability in basic and instrumental activities rose from 59.1% before to 85.4% after the age of 90 and cognitive impairment (Mini-Mental State Examination score ≤21) from 41.7% to 69.4%. Despite this and proximity to death, respectively 60.5% and 67.0% rated their health positively. Only one in five reported needing more help.

Conclusions: This study provides new data identifying high levels of physical and cognitive disability in very old people in the year before death. As the very old population rises, so will support needs for people dying in extreme old age. The mismatch between health perceptions and functional limitations suggests that these vulnerable older adults may not seek help from which they could benefit. These findings have major policy and planning implications for end-of-life care for the oldest old.
Place of death for the ‘oldest old’: ≥85-year-olds in the CC75C population-based cohort

Jane Fleming, Anouk Perrels, Jun Zhao, Morag Farquhar, Carol Brayne, Stephen Barclay and the Cambridge City over-75s Cohort (CC75C) study collaboration

Background: Deaths are rising fastest among the oldest old but data on their transitions in place of care at the end of life are scarce. Moreover, despite high prevalence of dementia close to death, ‘place of care’ trajectories for very old people approaching death with or without cognitive impairment are poorly described and understood.

Aim: To examine the place of residence or care of ≥85-year-olds less than a year before death, and their place of death, and to map changes between these settings for individuals across the cognitive spectrum.

Study design: Population-based cohort study

Setting: Cambridge City over-75s Cohort (CC75C) study

Method: Retrospective analysis of prospective data from males and females aged ≥85 years at death who died within a year of taking part in any CC75C survey (n = 320); death certificate linkage. Comparison of end of life transitions between groups of different cognitive status (sub-sample: n = 283 with cognitive assessments <1 year before death).

Results: Only 7% changed their address in their last year of life, yet 52% died somewhere other than their usual address at the time of death. Over two-thirds were living in the community when interviewed <1 year before death, but less than one-third who had lived at home died there (less than one-fifth in sheltered housing). Care homes were the usual address of most people dying there (77% in residential homes, 87% in nursing homes) but 15% of deaths in acute hospital came from care homes. Dying away from the ‘usual address’ was associated with cognition, overall fewer moving with increasing cognitive impairment – cognition intact 66%, mildly/moderately impaired 55% and severely impaired 42%, trend p = 0.003. This finding reflects transitions being far more common from the community than from institutions: 73% from the community and 28% from institutions did not die where last interviewed (p < 0.001). However, severely cognitively impaired people living in the community were the most likely group of all to move: 80% (68%–93%).

Conclusions: More than half the study sample of individuals of advanced old age had a change in their place of residence or care in their last year of life. These findings add weight to calls for improved end-of-life care in all settings, to avoid unnecessary transfers. The study data provide a baseline that can help plan and monitor initiatives to promote choice in location of care at the end of life for the very old.
Depression and anxiety: impact on service use in patients with advanced Chronic Obstructive Pulmonary Disease

Background: There is a high prevalence of anxiety and depression among people with Chronic Obstructive Pulmonary Disease (COPD). Anxiety and depression are associated with negative health outcomes and increased service use, particularly hospital admissions. Other demographic and health variables are also significant in this relationship. However, less is known about the nature of these relationships when COPD is advanced.

Aim: To identify the relationship between anxiety and depression and service use in patients with advanced COPD, and the role of demographic and health variables.

Methods: A population-based cohort of patients with advanced COPD recruited to the mixed-method Living with Breathlessness Study completed the Hospital Anxiety and Depression Scale (HADS) and reported hospital and community service use and experiences. Patient demographics and health variables were also collected. Quantitative analyses will explore relationships between anxiety and depression, service use, and demographic and health variables. Purposively sampled qualitative data analysed using a framework approach.

Results: 235 patients recruited: mean age 71.6 (SD 10.3); 61% male; mean MMRC dyspnea scale 3.68 (SD 1.040); mean CAT score 23.4 9 (SD7.5). Anxiety and depression scores (HADS) were higher than population norms. Relationships between anxiety and depression, service use, demographic and health variables will be reported quantitatively and qualitatively.

Conclusion: This analysis will provide new evidence on psychological health and service use in patients with advanced COPD. As part of an ongoing longitudinal study this data will inform trajectories of change in patient psychological health and service use to enable responsive service planning.
Barriers and facilitators to the uptake and maintenance of healthy behaviours by people at midlife: a systematic review

Sarah Kelly, Steven Martin, Isla Kuhn, Andy Cowan, Carol Brayne, Louise Lafontune

Abstract: Background: With an ageing global population, there is an increasing societal impact of ill health in later life. People who adopt healthy behaviours are more likely to age successfully. To engage people in health promotion initiatives in midlife, a good understanding is needed of why people do not undertake healthy behaviours or engage in unhealthy ones.

Methods: Searches (with no restrictions on country) were conducted to identify systematic reviews and qualitative or longitudinal cohort studies that reported midlife barriers and facilitators to health behaviour. Midlife ranged from 40 to 64 years, but younger adults in disadvantaged or minority groups were also eligible to reflect potential earlier disease onset.

Two reviewers independently conducted reference screening and study inclusion. Included studies were assessed for quality. Barriers and facilitators were identified and synthesised into broader themes to allow comparisons across behavioural risks.

Findings: From 16,426 titles reviewed, 28 qualitative studies, 11 longitudinal cohort studies and 46 systematic reviews were included. Evidence was found relating to uptake and maintenance of physical activity, diet and eating behaviours, smoking, alcohol, eye care, and other health promoting behaviours and grouped into six themes: health and quality of life, sociocultural factors, the physical environment, access, psychological factors, evidence relating to health inequalities. Most of the available evidence was from developed countries.

Barriers that recur across different health behaviours include lack of time (due to family, household and occupational responsibilities), access issues (to transport, facilities and resources), financial costs, entrenched attitudes and behaviours, restrictions in the physical environment, low socioeconomic status, lack of knowledge. Facilitators include a focus on enjoyment, health benefits including healthy ageing, social support, clear messages, and integration of behaviours into lifestyle. Specific issues relating to population and culture were identified relating to health inequalities.

Conclusions: The barriers and facilitators identified can inform the design of tailored interventions for people in midlife.
Healthy behaviours in people from disadvantaged and minority groups: evidence to inform the uptake and maintenance of healthy behaviours in people from disadvantaged and minority groups: findings from systematic reviews

Sarah Kelly¹, Steven Martin¹, Isla Kuhn², Andy Cowan¹, Olivia Remes¹, Carol Brayne¹, Louise Lafontune¹

¹Institute of Public Health, Forvie Site, University of Cambridge School of Clinical Medicine, Box 113 Cambridge Biomedical Campus, Cambridge CB2 0SR, UK

²University of Cambridge Medical Library, University of Cambridge School of Clinical Medicine, Box 111 Cambridge Biomedical Campus, Cambridge CB2 0SP, UK

Background: There is considerable potential for inequalities in health promoting behaviours and health outcomes arising from poverty, social and environmental factors. In relation to healthy ageing, there is potential for earlier disease onset including dementia, disability, frailty and non-communicable diseases in people from disadvantaged and minority groups. In order to engage people from disadvantaged or minority groups in health promotion initiatives and inform the design of effective interventions that consider their specific needs, a good understanding is needed of the existing evidence base. Additionally, identifying gaps in the evidence base can highlight areas where more information is needed.

Methods: Evidence relating specifically to inequalities was identified from three wide scope systematic reviews conducted using state of the art methodology to inform UK national guidelines on mid-life interventions to prevent or delay ill health in later life. Searches (to March 2014) were conducted to identify studies that reported 1) barriers and facilitators to uptake or maintenance of healthy behaviour 2) associations from longitudinal studies between health behaviour in early adulthood and mid-life (age 18 to 64) and health outcomes (dementia, disability, frailty and non-communicable chronic diseases) in later life 3) effectiveness of interventions to promote uptake of health behaviours. The evidence was synthesised narratively.

Findings: Several systematic reviews and primary studies described barriers and facilitators to health behaviours in black and minority ethnic groups (BME), socioeconomically disadvantaged or other minority groups, with little evidence from the UK. Specific barriers and facilitators relating to population and culture were identified, with issues of language and access as a recurrent theme. For associations between behavioural risk factors and later life outcomes, few studies specifically examined disadvantaged or minority groups. However, some evidence of effectiveness of interventions relating to physical activity, smoking and weight management was found in some ethnic minority groups, socioeconomically disadvantaged groups and homeless populations.

Conclusions: The evidence base relating to health behaviours in disadvantaged and minority groups is limited. More evidence is needed to understand behavioural risks and factors that influence uptake and maintenance of health behaviours in these populations.
COMMON GENETIC VARIATION AND RISK PREDICTION IN BREAST CANCER "Nasim Mavaddat, Kyriaki Michailidou, Douglas Easton on behalf of the Breast Cancer Association Consortium

Stratification of women according to the risk of developing breast cancer can improve risk reduction and screening strategies by targeting those most likely to benefit. Polygenic risk scores (PRSs) summarizing the effect of common, low risk susceptibility variants facilitate risk stratification. Genome-wide association studies have identified ~100 loci at genome-wide significance, but the combined predictive value of these loci is still limited.

The aim of this study was to determine whether including sub-genome wide significant SNPs in the PRS could improve on risk prediction obtained using SNPs with confirmed associations. Participants were 48,155 cases and 43,612 controls from 41 studies in the Breast Cancer Association Consortium. Samples were genotyped using a custom Illumina array (~200,000 genotyped (iCOGS), and ~9 million imputed SNPs). The dataset was divided into training (90%) and test (10%) sets. ‘Top hits’ were selected using data independent of the test set, and SNPs within 500Kb of the ‘top hits’ excluded. SNPs were pre-selected at various liberal training set p-value thresholds. Methods compared included subset selection and penalized regression using lasso, elastic net and ridge regression.

PRSs including SNPs selected at liberal training set p-value thresholds were significantly associated with breast cancer risk in the test set, consistent with the hypothesis that sub genome-wide associated SNPs contribute to breast cancer risk. Inclusion of sub genome-wide SNPs (p<0.002) in the PRS resulted in a small but statistically significant improvement in risk discrimination over PRSs constructed from SNPs with confirmed associations (AUC 0.633 vs 0.620). Risk prediction for breast cancer may be improved using methods that better model the underlying genetic architecture of the disease, by incorporating genomic features to help delineate true signals from noise, and by further resolving causal variants in known susceptibility regions."
Barriers and facilitators to primary care clinicians’ ability to meet the needs of patients with advanced COPD and their carers

Aim: Advanced chronic obstructive pulmonary disease (COPD) management should relieve symptoms, optimise daily functioning and reduce carer burden, yet we know little about clinician barriers and facilitators to meeting the needs of these patients and their carers. We aimed to identify barriers and facilitators to primary care clinicians’ ability to meet needs in advanced COPD.

Method: Audio-recorded qualitative topic-guided interviews with 34 primary care clinicians nominated by a population-based cohort of patients with advanced COPD participating in the multiple-perspective mixed-method “Living with Breathlessness” study. Verbatim transcripts analysed using a framework approach.

Results: Participating clinicians included GPs, practice nurses, nurse practitioners and community matrons. Clinician-identified barriers included: managing co-morbidities, lack of referable services, lack of regular or structured patient assessments, communication difficulties, and limited engagement with carers. The lack of clinician knowledge of the presence and needs of carers was noteworthy. Clinician-identified facilitators included: trust, communication skills, their educational role and accessibility.

Conclusion: Barriers and facilitators to meeting needs in advanced COPD exist for clinicians. Strategies to address these barriers are required in order to improve care and support of patients and carers. The Living with Breathlessness study seeks to achieve this through working with stakeholders, including clinicians, to co-develop actionable responses to the study’s multiple-perspective findings.”
What do informal carers want to learn about breathlessness in advanced disease and how do they want to learn it?

"Introduction: Breathlessness is a distressing, disabling symptom of advanced disease with considerable impact on informal carers. We know that carers experience anxiety, isolation, restriction of activity, lack of support and powerlessness. Despite this knowledge the evidence-base for educational interventions to support informal carers and enhance their caregiving capacity is limited.

Aims/Method: To identify informal carer preferences for learning content and delivery modes of an educational intervention for carers on breathlessness in advanced disease. In-depth interviews with a purposive sample of 24 patient-carer dyads from two disease groups (cancer and COPD) to facilitate exploration of similarities and differences in education needs and preferences for differing disease trajectories. Analysed using a Framework approach.

Results: There was a notable degree of overlap in content and delivery-mode preferences among informal carers across the two disease trajectories. Five areas of learning were salient for carers: understanding breathlessness (causes and experience); managing anxiety and panic; helpful and safe levels of activity; maintaining quality of life; and, knowing what to expect in the future. Intervention delivery-mode preferences included face-to-face group learning incorporating clinical-practitioner expertise and a supportive element through sharing experiences, ‘work-arounds’ and useful tips with peers. Carers generally wanted to learn with their patient so short sessions, not too early in the day, in venues accessible for breathless patients were important practical considerations.

Conclusion: An evidence-based educational intervention needs to be broad in scope, incorporating both clinical-practitioner expertise and peer experience. It should also be flexible to accommodate a variety of delivery-mode preferences and personalised content."
Pathogen genomics into practice; policy to support the genomic transformation in infectious disease services

The PHG Foundation is an independent health policy think-tank with the mission to achieve responsible and evidence based application of biomedical science for health. The Foundation has been engaged on a major project spanning 18 months to assess the potential impact of microbial genomics on public health and health services and develop policy to support implementation. The goal of this work was to identify and describe the actions that need to be taken to meet the aim of:

• ‘Supporting the development and delivery of genomics informed infectious disease services that are evidence based, high quality, available population-wide, and on an equitable basis’.

Our report, a synthesis of in-house research and stakeholder consultation, reviews the current state of science and clinical practice in pathogen genomics, and details 35 recommendations to achieve the above goal. The results clearly show that the effectiveness of any efforts to implement pathogen genomics will depend on the implementation of a nationally coordinated system of service development and delivery. Two essential features of this system are:

• Data integration: of all genomic and clinical data generated during public health/clinical investigations, for enabling the delivery and development of services.
• Strategic coordination and leadership: across the organisations involved in delivering and using pathogen genomics to achieve effective and efficient services; e.g. by sharing expertise, and agreeing best practice and standards.

These features and others are discussed in depth in our report: Pathogen Genomics into Practice.
15. Dr Sumantra Ray  
Chair of the Need for Nutrition/Innovation Programme, MRC Human Nutrition Research

THE 'NELICO' India Project: building research capacity in public health initiatives – from local to global

Building research capacity through empowerment of clinical and public health practitioners is key to the join up between evidence and practice. This is particularly important in Asian countries where resources are variable and evidence based practice is still heavily reliant on Western data. The NELICO India project attempts to address this issue through a potentially low cost but impactful and sustainable approach to research capacity building in the practitioner workforce with the ultimate goal of generating local evidence of global quality to inform healthcare practice.

16. Dr Gurdeep Sagoo  
Health Economist, PHG Foundation (Health Economist)

Clinical utility of gene panel testing: Case study using a 65-patient Dementia cohort

"The increasing availability and affordability of whole exome sequencing is challenging the current testing algorithms typically including detailed family history and clinical characteristics, predicting a decrease for the need of probabilistic prioritisation of genetic testing. To evaluate this prediction, we have assessed a cohort of 65 patients referred for frontotemporal dementia (FTD) and compared the diagnostic yield of the initial referrals for single gene tests vs. a 16-gene dementia panel test using our clinical exome sequencing pipeline. This 16-gene panel includes mostly autosomal dominant rare Mendelian early onset Alzheimer and FTD genes, that despite being clinically different show a degree of phenotypic overlap justifying the use of a panel.

Although this approach has the clear potential to increase the diagnostic rate, we also aimed to determine its usefulness vs. the burden of finding variants of unknown clinical significance (VUS). Analysis showed a diagnostic rate of 6/65 for the initial targeted referrals with 4/65 VUS. Subsequent interpretation of panel data increased this rate to 7/65 for published pathogenic variants and added 19 variants which we are currently assessing for pathogenicity, including 3 PSEN2 variants reported in the AD&FTD database. Preliminary results on this small FTD cohort indicate that despite the complexity of the interpretation of gene panel data, the increase in diagnostic rate together with value for money should encourage clinicians to refer for gene panels."
Public Health and Prisons – care options for older prisoners with general frailty and long-term conditions

Caroline Lee, Anna Haggith, Frances Cater, Barney Eden, Isla Kuhn, Natalie Mann, Tine Van Bortel

Summary:
The growing prison estate population is posing significant public health problems, locally (UK) as well as globally. Within this prison population, the fastest growing group is the older prison population, and related health issues. The care of older prisoners with ‘general frailty’ and long-term conditions such as cancer, CVD, stroke, mental health problems and dementia in British prisons is an increasing challenge and ever growing. Older prisoners can have problems with: (1) mobility; (2) appropriateness of activities on offer to age and health status; (3) social and personal care needs. Provisions and standards of social care for older people in prison vary and fall short of that in the community, even though government policy states that prisoners should have access to the same level of care in prison as they would in free society. With future demand expected to rise (as numbers of over 50s and over 65s are projected to grow beyond current levels) we have looked at the best health & social care models in terms of effectiveness, cost-effectiveness, infrastructural and financial sustainability.
Targeting health inequalities and evidence gaps for exercise-based rehabilitation for older, multi-morbid community based populations with heart failure.

Authors: J. Fleming*, I. Wellwood*, F. Early†, K. Carver†, C. Deaton*
Affiliations: *Cambridge Institute of Public Health, †Cambridge University Hospitals Foundation NHS Trust

Background: Analysis of Clinical Practice Research Datalink (CPRD) data shows 13.1% of men and 11.9% of women aged over 75 years in the UK suffer from heart failure (HF) (British Heart Foundation (BHF) 2013). Trials evidence (mostly from younger, male populations) shows benefit of exercise after cardiac disease, yet national audits show the proportion of HF patients referred to exercise-based cardiac rehabilitation (CR) programmes after hospitalization is limited (11%), falls short of the 43% national target and has discrepancies by gender and age. To identify relevant issues and develop hypotheses for collaborative multidisciplinary health services research we wanted to understand service delivery and patients’ experiences of cardiac rehabilitation and community exercise.

Methods: In late 2014 we involved patients and public (PPI) in qualitative exploratory focus groups and informal interviews with members of CR groups run by NHS and community based exercise providers in the East of England. A topic guide included levels of activity and exercise, barriers and facilitators to exercising and attending groups. Meetings with professionals and carers provided supplementary data.

Results: Over 50 participants from 9 groups across 5 sites provided comments. Activities reported varied from doing “not much” to walking, gardening, cycling and charity runs. Themes identified included:

- Importance of social support from peers, and professionals e.g. community HF nurse, exercise instructor.
- Flexible, individualized approaches.
- Invitation to classes and early encouragement.
- Options for follow up e.g. review by health professionals
- Use of technology; such as pedometers, home exercise DVDs.
- Practical considerations included transport, parking, traffic.

Conclusion: Early engagement with patients and services has been important in informing our proposals. Information will be incorporated into funding applications for a research programme around exercise-based rehabilitation for HF, led by the Clinical Nursing Research group (CNRG), targeting health inequalities and gaps in evidence for older, multi-morbid, community based populations.
Implementing evidence-based Pulmonary Rehabilitation (PR) in the East of England (EoE): examining equity of referral and uptake across the EoE Respiratory Strategic Clinical Network (EoERSCN)

Authors:  F. Early†, I. Wellwood*, L. Jongepier‡, R. Barlow◊‡, J. Fuld†, C. Deaton*
† Cambridge University Hospitals Foundation NHS Trust
* Cambridge Institute of Public Health
‡ East of England Respiratory Strategic Clinical Networks, NHS England
◊ Provide, COPD team, Chelmsford, Essex

Background: Approximately 975,000 people were diagnosed with chronic obstructive pulmonary disease (COPD) in England in 2012-13; many experiencing breathlessness, exercise incapacity and worsening health, with exacerbations frequently requiring costly hospitalisation. NICE (2011) recommends pulmonary rehabilitation (PR) to provide supervised exercise and education. PR has short term impacts on symptoms, improves exercise capacity and quality of life and helps develop self-management skills. However, service evaluation data from the East of England Respiratory Strategic Clinical Network (EoERSCN), demonstrate specific challenges implementing PR in practice: 1) referral and uptake, 2) attendance, completion and adherence to exercise and 3) patients who do not achieve clinically meaningful improvements. The Clinical Nursing Research Group (CNRG) is leading development of a multi-disciplinary, collaborative funding proposal aiming to understand the modifiable barriers to accessing PR and to develop interventions which improve equity of services.

Methods: Preparatory research will include: 1). A systematic literature review. 2). Descriptive analysis of a retrospective sample of routinely gathered, anonymized, patient-level data from different centres in the EoERSCN database. 3). Engagement with patient and public (PPI), to assist our understanding of patients’ experiences of PR, referral and assessment and identify lay advisors.

In the main study, Normalisation Process Theory (NPT) will provide the theoretical framework for qualitative observational field work to identify factors that facilitate and inhibit referral, assessment and uptake from multiple perspectives.

Early stages will inform the development and testing of an intervention targeting improvements in referral and uptake to PR.

Conclusion: The multi-disciplinary approach, patient engagement and strong theoretical framework underpinning the study will allow the systematic examination of implementation of PR services across the East of England. Modifiable barriers will be targeted in interventions aiming to improve equity of access to PR services with potential impacts on the quality of service delivery and commissioning.