National Institute for
Health Research

Abstract Booklet

PhD Network Forum

NIHR Patient Safety Translational Research Centres

5th February 2019

The Studio, Leeds

Delegate Agenda

9.30am – 10.00am **Registration and refreshments**

10.00am – 10.15am **Welcome**

Professor Rebecca Lawton

10.15am – 11.15am **Student presentations (Sessions A and B)**

Two parallel sessions chaired by Dr Gill Janes & Dr Søren Rud Kristensen

11.15am – 11.30am **Coffee break**

11.30am – 12.00pm **NIHR Academy training opportunities**

Karen Fernando

12.00pm – 12.30pm **The methodological challenges of designing research on the economics of patient safety**

Professor Rachel Elliott

12.30pm – 1.30pm **Networking lunch, poster presentations**

1.30pm – 2.30pm **Student presentations (Sessions C and D)**

Two parallel sessions chaired by Dr Jonathan Benn & Dr Beth Fylan

2.30pm – 2.50pm **Involving marginalised groups in patient safety research**

Dr Caroline Sanders

2.50pm – 3.15pm **Maximising the impact of your research**

Professor Rebecca Lawton

3.15pm – 3.30pm **Event close**

Professor Stephen Campbell

Poster Abstracts

Patient-controlled electronic health record (EHR): patients' preferences and expectations – preliminary results of an interview study.

Lisa Freise (Imperial PSTRC)

Background: Electronic health records (EHR) have the potential to improve quality of care, and in particular to enhance patient-centeredness, safety, and effectiveness. However, low adoption rates and patient perceived usefulness of the system may hinder the potential of this technology. **Aims:** The aim of this study was to evaluate the implementation of an EHR, the Care Information Exchange (CIE) in North-West London and, specifically, to assess patients' preferences and expectations regarding its use. **Methods:** Patients from two services (Colposcopy and Rheumatology) that actively enrolled patients to the Care Information Exchange (CIE), an EHR initiative in North-West London, participated in semi-structured interviews. The interviews were audio recorded with explicit permission from the participants and transcribed by LF. The transcripts were analysed thematically by a researcher and three trained patient representatives. **Results:** The interviewees (n=31, 84% female) had prior experience of using the CIE in 29% of the interviews. The themes identified in the analysis revolved around a) patients' motivation to use the CIE, b) their ability to do so including barriers and enablers for it, c) their concerns and potential weaknesses of the CIE, and d) preferences for and perceived strengths of the CIE. **Conclusions:** The interviews gave valuable insights into patients' preferences and concerns regarding CIE use. To enhance the impact of patient access to EHRs on quality of care, the perceived barriers and problems of the system need to be addressed through a review of the CIE design in order to further develop the usefulness of the patient-centred information platform to patients.

Quality and continuity of medication management systems when people living with dementia move between the care home and hospital setting.

Suzanne Hill (Yorkshire and Humber PSTRC)

Background: The transfer of complete and accurate information at the care home/ hospital transition is important for patient safety; efficiency and continuity of care (Cwinn et.al, 2009; Boockvar et.al 2006; King et.al, 2013). People with dementia may find communication difficult and they are also less likely to identify that medication is incorrect (Maidment et.al, 2008). Transitions between acute and long-term care settings are complex and developing interventions which protect this vulnerable population are vital (Chabbra et.al, 2012). **Aim:** To investigate the quality and continuity of medication management (MM) for people with dementia at the care home/hospital transition. (NB: *Quality definition (IoM, 2001): Safe; effective; timely; efficient; person-centred; equitable). **Study Design/ Methods:** Multi-method, qualitative study across three care home (Nursing, Mixed and Residential) and two hospital sites. Phase I (Care Home): Policy analysis and 22 semi-structured interviews (3 nurses; 9 senior carers; 7 residents and 3 family members). Phase II (Hospital): Recruitment ongoing across two hospital sites: Policy analysis and 12 multidisciplinary staff interviews. **Analysis:** Care home policy analysis and thematic analysis of interview transcripts ongoing. Preliminary themes (phase I) include: Evidence informing quality and continuity of MM at transition (policy/evidence; staff expertise/experience; resident and family involvement); Factors influencing the quality and continuity of MM at transition (contextual factors; organisational factors); Cross-boundary working/Interdisciplinary relationships (Empathy/understanding; power relations etc). **Outputs:** Make recommendation for components of a future intervention to improve the quality and continuity of medication management for people with dementia when they move between the care home and hospital setting.

Understanding the barriers and facilitators of implementing NICE guidelines for self-harm.

Jessica Leather (Greater Manchester PSTRC)

Background: Primary care is an opportune setting to identify and support people who may be at risk of suicide. Self-harm is a risk factor for suicide, and patients who have self-harmed tend to consult more frequently than those who have not. Presentations for self-harm represent an opportunity for healthcare professionals to prevent suicidal behaviour, but some primary care practitioners feel they are unable to implement national guidelines for suicide and self-harm prevention. There is a need to identify which healthcare professionals feel they need support to assess and manage self-harm. **Aims:** This project aims to identify how many healthcare professionals, and in which settings, encounter patients who may self-harm. We will explore clinicians' experiences of these encounters, and examine whether implementation of guidelines is associated with the availability of training and resources. Additionally, we aim to assess the awareness and implementation of NICE guidelines for self-harm, and identify any barriers that prevent professionals from doing so. **Methods:** A nationally representative online survey of one thousand healthcare professionals, followed by semi-structured telephone interviews with forty-five respondents to the survey.

How do NHS staff respond to online patient feedback? A typology of responses published on Care Opinion.

Lauren Ramsey (Yorkshire and Humber PSTRC)

Background: Patients are increasingly reporting about their healthcare experiences in a public and non-politicised manner online. This has been facilitated by the digital culture of the 21st century, the growing focus on transparency in healthcare and a desire for patient anonymity. The objective of this study was to identify the types of responses that staff provide on Care Opinion (www.careopinion.org.uk), a not-for-profit online platform on which patients are able to provide feedback regarding health and social care in the UK using a free text narrative. **Methods:** Framework analysis was used to qualitatively analyse a purposive sample of 486 stories regarding hospital care, and their responses. **Results:** The ways in which staff responded to online patient feedback varied. They key variables included the extent to which responses were bespoke, and personalised to the specific issues raised, and the extent to which the responder embraced the transparent nature of online discussion in the public domain. Additionally, the extent to which the responder suggested that the feedback had led to learning, and would impact on subsequent care varied. Five typologies of staff responses to online patient feedback were identified. This included; non-responses, generic responses, appreciative responses, offline responses and transparent, conversational responses. **Conclusion:** This study advances the relatively unexplored area of online patient feedback, having practical and theoretical implications for those looking to use online patient feedback to inform improvement. Future research should focus on the relationship between staff response type, and the ways in which online patient feedback is used in practice.

Can tools promoting team reflexivity improve teamwork and communication in inter-professional hospital-based healthcare teams? A systematic review.

Siobhan McHugh (Yorkshire and Humber PSTRC)

Background: Effective teamwork and communication have been clearly identified as fundamental to patient safety. Consequently, failures in teamwork and communication have been identified as contributing factors to medical error and compromised patient safety. Thus, interventions targeting such process and relational aspects of care may provide safety solutions better aligned with the complex nature of healthcare provision. Team reflexivity is one such approach, focused on the development of a continuous process of learning, allowing teams to develop an understanding of the collective values that inform action. There is currently little evidence regarding the use of reflexivity to promote learning or practice improvement in inter-professional healthcare teams. **Aims:** This review aimed to understand how reflexivity has been used in healthcare teams, how staff respond to different methods of team reflexivity, and whether team reflexivity can effect change in inter-professional teamwork and communication. **Methods:** The search strategy was applied to five databases from 1990 to the present day. As the use of reflexivity in healthcare is a focal area of research with a small number of research groups, the lead authors in these groups were also contacted during the initial search. Reflexivity, for the purposes of this search, was defined as '*a tool that allows broader attention to routine working practices, providing renewed awareness and discussion of taken-as-given processes and interactions*'. Studies of any naturally-occurring hospital-based healthcare teams were included, where outcomes primarily focused on any measure or discussion of impact on teamwork, inter-professional communication and collective values. Studies of healthcare teams working outside of tertiary care were excluded. **Results:** 2566 titles were identified after the removal of duplicates. Following screening and full-text review, 16 articles met the inclusion criteria and were included in the review. Simulation training (n=8) and video-reflexive ethnography (VRE; n=7)) were the most commonly reported forms of team reflexivity. It was also applied within reciprocal peer review (n=1). Articles were set out to; engender optimisation of daily practice (n=4), evaluate specific reflexive methods (n=7), and improve safe and effective teamwork (n=4). The use of reflexive feedback is reported as successful in allowing staff to explore the complexities of their daily work, however no formal measures of staff acceptability or research feasibility were reported. Improvements in inter-professional communication was reported in the majority of studies (n=11), although improvements in working environment and specific clinical processes were also reported (n=5). **Conclusions:** Team reflexivity encourages healthcare professionals to focus on improvements in the process and relational aspects of care. The reviewed literature suggests that VRE is best placed to allow staff to develop locally-appropriate solutions to process and relational issues identified from footage of in-situ practice. Continued focus must be on the development of more high-quality research and reporting to explore how this method can be integrated into acute, high-risk organisations.

Mapping drug related problems among hospitalised children and young people in the united kingdom: An initial analysis of a systematic review.

Adam Sutherland (Greater Manchester PSTRC)

Background: Drug-related Problems (DRPs) are defined as "an event or circumstance involving drug therapy that actually or potentially interferes with desired health outcomes" (1) and include medication errors (MEs), adverse drug reactions (ADRs), and patient-related factors including adherence. Medication use in hospitals is complex, with DRPs being associated with harm. The

World Health Organisation (WHO) has set the challenge to reduce avoidable medication-related harm by 50% within 5 years (2). This requires targeted interventions, however these interventions must be systems focussed (3) and existing interventions are poorly designed and evaluated (4). **Objectives:** To undertake a systematic review of the literature relating to the prevalence DRPs in hospitalised children and young people, and to identify where in the medication process they occur. **Methods:** Nine databases were searched in September 2018, from 1999 to the present day. CYP were defined as anyone <18 years of age, admitted to a hospital environment in the UK. Observational and intervention studies written in English were included where there was a clear denominator and sufficient data to calculate an event rate. The citation lists of included studies were hand searched for additional studies. Specialist care areas (NICU/PICU) were excluded. The primary outcome of interest was the rate of DRPs experienced by hospitalised CYPs. **Results:** 34414 titles were identified which after screening and review were reduced to 28 included studies. Studies examined information communication (n=3), MEs (n=13), ADRs (n=5) and DRPs (n=7). Incidence data was available for 7993 patients, with DRPs affecting 3034 (38%). Information communication discrepancies affected 64.7% (33-83%) of patients. ADRs affected 34.2% (28.2-59.4%) patients and DRPs were observed in 70.3% (34-160%) patients. ME rates were only calculated on a per-order basis with no patient-level data observed. DRPs were apparent at all stages in the medication process, with the majority associated with prescribing and administration of medicines. **Discussion and Conclusions:** The prevalence of DRPs in hospitals is substantial, and higher than other published reviews focussed on specific processes may suggest. There is now a need to examine and study the systems to explain WHY these high rates are so prevalent, and to begin designing more robust interventions.

Oral Presentation Abstracts

Session A

Session title: Supporting workforce development and wellbeing to promote patient safety
Location: Matter (7th Floor)

Evaluating the use of video-reflexive ethnography to improve teamwork and communication during multi-disciplinary labour ward handovers.

Siobhan McHugh (Yorkshire and Humber PSTRC)

Background: Following a series of high-profile patient safety events, the quality and safety of maternity provision has come under scrutiny, leading to the commissioning of a national report of UK maternity services. The '*Better Births*' publication reported rising numbers of complex births and caesarean sections, reflected in the complex and often transient staff teams working on NHS labour wards. The increasing complexity of healthcare provision subsequently leads to increasingly complex daily communications and working practices, particularly the multi-disciplinary handover which occurs twice daily on the labour ward. In response to staff reports of poor communication, and the need for better communication between disciplines, the report recommends efforts to improve multi-disciplinary communication and practice. Video-reflexive ethnography has been identified as a potential method for the improvement of these process and relational elements of healthcare provision. VRE combines ethnographic methods with in-situ filming of specific working practices. Reflexive viewing of edited footage allows healthcare professionals to work collaboratively to learn about the complexities of routine practices, to understand the local risks, and to develop solutions to optimise local practice. Despite reported success, there is currently little theoretical underpinning of the method, and little understanding of how this method can be applied with multi-disciplinary teams working in acute maternity services. **Aims:** This project aims to evaluate video-reflexive ethnography (VRE) as a potential tool for the improvement of teamwork and communication within multi-disciplinary labour ward teams, focusing specifically on the clinical handover. We will attempt to develop further understanding of the feasibility and acceptability of using VRE in acute healthcare environments. The project also aims to determine the success of VRE in generating staff-led suggestions for, and implementation of, improvements in teamwork and communication during multi-disciplinary handover. **Methods:** Following six-months of ethnographic observations on labour ward, six multi-disciplinary handovers were filmed over a two-month period. 60 staff provided consent to be filmed, with some cross-over in the staff filmed over the six handovers. Staff were also asked to answer a short survey designed to capture how comfortable they felt giving information during the handover, and whether they felt the handover provided enough information for them to safely carry out their shift. Films were edited in collaboration with an independent clinician, and the resulting clips were designed to reflect routine daily practice. To date, the edited clips have been shown to staff during three reflexive feedback sessions. The aim will be to ensure all staff grades have been included in reflexive feedback sessions. **Future Work:** Improvements discussed in the reflexive feedback sessions will be presented to the relevant trust staff, and implementation of improvement will be captured using focused ethnographic observations and in-situ filming. Staff will be asked to complete another short survey and the results of pre- and post-improvement surveys will be analysed to capture reported improvement in communication. Semi-structured interviews with staff following reflexive feedback sessions aim to capture the acceptability of the method, staff engagement in VRE, and perceived improvements in communication and teamwork during the handover and more generally on labour ward.

Identifying and developing non-technical skills in community pharmacy to improve patient safety.

Ahmed Ashour (Greater Manchester PSTRC)

Background: In England, the number of medication errors occurring yearly has been put at 237 million (Elliott et al., 2018). In the year 2016/2017, 1.01 billion items were dispensed by community pharmacies (NHS Digital, 2017), with some studies suggesting that the percentage of dispensing errors is at 3% (Franklin and O'Grady, 2007). Research into the cause of some of these errors in community pharmacy has mainly focused on retrospective analysis of incidents, rather than highlighting issues in the education and development of the pharmacists. With the increasing number of services that are being commissioned from community pharmacists, and the increasing number of medicines dispensed, it is important to understand how community pharmacists are completing tasks and what non-technical skills are required by them in order to practice safely and efficiently. **Aims:** This PhD aims to identify and develop the non-technical skills of community pharmacists, to improve patient safety. **Method:** In order to identify the Non-Technical Skills (NTS) required for community pharmacists to complete their role efficiently and safely, it is proposed initially conducting a task analysis on tasks pharmacists complete in practice. This will be done through producing a Hierarchical Task Analysis (HTA), using focus groups and observations with subject matter experts (i.e. community pharmacists). Semi-structured interviews will then take place to better understand which skills are used in practice and how. The results from the initial studies will be presented to a group of subject matter experts who will use the data to produce a prototype behavioural marker system. **Results:** HTAs for different tasks that community pharmacists complete are currently being validated through observations, with tasks such as conducting the New Medicine Service (NMS) and the NHS Urgent Medicine Supply Advanced Service (NUMSAS) making up a larger set of 20 tasks that will form this framework. **Future Work:** It is anticipated that the developed HTA will act as a framework to better understand the way pharmacists conduct their tasks and allow further collaborative research between HFE experts and pharmacy practice research. Next steps in this PhD will be conducting the qualitative interviews with community pharmacist to identify the Non-Technical Skills that are required by them to complete their role safely and effectively, utilising the validated HTA as a foundation. Following this, the prototype behavioural marker system will be developed and evaluated for a number of factors including validity and reliability.

Self-affirmation, wellbeing and patient safety perceptions in hospital nursing: How effective are self-affirmation interventions for improving levels of wellbeing?

Alice Dunning (Yorkshire and Humber PSTRC)

The poor levels of wellbeing among healthcare professionals and especially nurses has been given increasing attention in the media and also from research and policy perspectives. This is unsurprising because of the consequences for patient safety, staffing levels and cost. Values which have always held high importance within the nursing profession; have also been linked with levels of burnout, job satisfaction and turnover. Whilst there have been interventions implemented to help improve wellbeing for nurses, many of these have been face to face and thus demanding upon resources. Therefore there is a requirement for interventions to be available in a self-administered format in order to be more accessible to the nursing workforce. An intervention that is usually self-administered and focuses upon values is self- affirmation. Self-affirmation interventions have been used in research previously to help improve levels of wellbeing, but have yet to be implemented for this purpose with nurses. This PhD aims to investigate how feasible and effective a self-affirmation intervention could be for improving levels of wellbeing and perceptions of patient safety among nurses. This intervention will be adapted using information from interviews and workshops held with nurses; in addition to a systematic review looking at self-affirmation and its effectiveness in improving wellbeing. Once adapted, the intervention will be piloted and evaluated. This presentation will cover the studies currently underway and the future plans for the project.

Session B

Session title: Adverse events and complaints: management, investigations and economic impact
Location: Mind (7th Floor)

Does the outcome of a patient safety incident affect what recommendations we make?

William Lea (Yorkshire and Humber PSTRC)

Background: In a typical trust, 900 patient safety incidents (PSI) are reported each month1 and are subject to investigations, with an average of 5 recommendations being made2. There is, however, some evidence of bias in the decision making processes around what should be investigated and what recommendations are appropriate, with those events that result in serious harm and death being associated with perceptions of greater individual culpability, more thorough investigations and a need for 'stronger' recommendations 3,4,5. In this study we will test the hypothesis that the outcome of a PSI influences the types of recommendations proposed. **Aims:** To test the hypothesis that outcome of a PSI affects the types of recommendations that healthcare workers or members of the public might propose following an investigation. **Methods:** Three fictitious PSI scenarios with a list of possible recommendations will be presented to participants, who will be asked to rank the recommendations in terms of how effective they would be in reducing the risk of the incident re-occurring. The outcome of each scenario will be varied (no harm, moderate harm, death) so that each participant receives three scenarios, each with a different level of harm. Data will be collected using a survey questionnaire which will be distributed to three different participant groups; public, frontline healthcare staff, healthcare staff with patient safety/investigation experience or expertise. A prior power analysis was performed (alpha 0.05, power 0.8, effect size 0.25) estimating a total sample size of 98. Single scores based on the participants recommendation choices will be calculated, the dependant variable, while the scenario with varying outcomes will be the principle independent variable. A repeated measures analysis will be used to determine the effect of PSI outcome on recommendation selection.

Protocol to investigate patient harm and costs associated with hazardous prescribing of antithrombotics in primary care using real world data.

Leonie Brinkman (Greater Manchester PSTRC)

Background: The reduction of prescribing errors (PEs) recently became a policy objective of the UK government. To date information on PEs' associated harm and costs is sparse. Therefore, this protocol describes how data will be generated to link PEs with patient harm and resource use. The study will focus on PEs related to antithrombotic drugs, because of the enormous impact of these PE's on patient's quality of life, mortality and health care costs. **Method/Design:** An observational cohort study will be conducted using linked primary and secondary care health records (CPRD GOLD, HES and ONS). The population consists of patients at risk of predefined PEs that were previously identified through a rigorous consensus process and were deemed to be most likely associated with harm. Each PE will be analysed in a separate cohort. Patients from the cohort are exposed once the hazardous prescription is prescribed, hence the PE occurs. Primary serious harm outcome will be gastrointestinal bleeding (GIB). Secondary outcomes are resource use, mortality, intracranial haemorrhage (ICH) and major bleeding. Survival analysis methods will be used to model time to bleeding events and deaths in each of the exposed and unexposed error cohorts. The association between hazardous prescribing and total healthcare resource use will be estimated using a generalized linear model (GLM) and appropriate unit costs will be applied. **Conclusion:** This protocol presented here was designed for estimating the burden of specific PEs. However, the methodology I propose could be adapted to estimate the burden of various prescribing errors in a real world setting.

Improving organisational listening to patient complaints: Testing complaints analysis frameworks to extract patient voice

Jackie Van Dael (Imperial PSTRC)

Introduction: Patient complaints provide a valuable source of insight into safety-related problems within healthcare organisations. They are sensitive to, and able to recognise, a range of problems in healthcare delivery, not always identified by traditional systems of healthcare monitoring (e.g. incident reporting systems, retrospective case reviews), including continuity of care, systemic problems, and unfinished or omitted care. Whilst academic and public survey evidence consistently finds that patients and families primarily complain to drive quality improvement and prevent errors from happening to others, learning from complaints has been hindered by the lack of reliable and systematic complaints management in the NHS. The 'Healthcare Complaints Analysis Tool' (HCAT) was developed by researchers in our team to overcome these limitations and reliably distinguish and codify problem type, problem severity, level of harm caused, stage of care where each problem occurred, and the staff groups implicated, as referred to in complaints. In contrast to KO41, HCAT is theoretically informed, and has been tested for inter-rater reliability (i.e. do different reviewers code the same complaint in the same way) and discriminant content validity (i.e. do categories measure what they are intended to measure and are they mutually exclusive). However, the strength of HCAT has yet to be established within healthcare organisations, when used by complaints handlers, applied to non-redacted samples of complaints. Secondly, there is no research that examines the patient-centredness of complaints analysis tools. Although HCAT has been tested for "discriminant content validity" (i.e. users find categories understandable and the categories are mutually exclusive), it is largely unknown whether patients and families feel that coded categories accurately reflect concerns as voiced in the complaints. **Aims:** To examine whether the current NHS complaints analysis framework (KO41) accurately classifies patient reported problems in complaints and supports reliable and patient-centred analysis for organisational learning and quality improvement, and trial an alternative complaints analysis intervention (HCAT). **Proposed method:** Inter-rater reliability of current NHS complaints recording will be tested by asking two independent groups, 'neutral' coders and complaints admin staff, to classify an identical sample of complaints and PALS (n=150) with the KO41 framework. Using the same complaints and PALS dataset, staff and patients will then code once again using the HCAT framework. Inter-rater reliability scores will be compared between both tools to assess which tool is better at place to reliably extract problem types from complaints and support aggregated analysis for service monitoring and improvement. Patient-centredness will be examined by presenting participants (patients and family) with anonymised complaints and coded categories of either HCAT or KO41a. A numerical rating scale will be used to assess level of confidence per item (i.e., "from 0-10, how confident are you that the coded category reflects the problem reported by the complainant?). **Anticipated results:** This study will identify which tool is better to derive patient insights from complaints for quality improvement. It will also demonstrate whether each tool fulfils the minimum standards and identify categories in each framework that need to be revised. Examples of HCAT analysis output will be presented at the Forum.

Session C

Session title: Involving and engaging patients for patient safety.
Location: Matter (7th Floor)

Patient-controlled electronic health record (EHR): patients' ability to understand health information and identify potential errors.

Lisa Freise (Imperial PSTRC)

Background: Patient-controlled EHR have the potential to improve patient safety, e.g. by increasing detection of errors in medical records. To achieve this, patients need to be able to understand the information contained in their EHR, and to have the skills to identify potential errors. **Aims:** This study aimed to assess a) patients' ability to understand EHR information, b) barriers that prevent their understanding, and c) patients' ability to identify errors in EHRs. **Methods:** Patients using the Care Information Exchange (CIE), an EHR initiative in North-West London, responded to an online survey during March 2017 – September 2017. Qualitative data was analysed thematically according to the framework analysis methodology. Quantitative data was analysed descriptively. **Results:** A total of 210 patients completed the survey. The majority of respondents did not report problems in understanding EHR information (68.7%, *n*=179). Barriers to understanding were related to information (i.e. medical terminology and knowledge; interpretation of test results) and technology (i.e. user-friendliness, website layout; result presentation) issues. Almost 14% (*n*=187) of the participants identified errors including incorrect information (i.e. contact information; appointment details; results and measurements) and incomplete information (i.e. appointment details; results). **Conclusions:** While the majority of patients did not report difficulties in understanding EHR information, information and technology based barriers still persist. To enhance the impact of patient access to EHRs on error correction, these barriers need to be addressed and used to inform the development of patient-centred information platforms.

Understanding and enabling Patient and Public Involvement and Engagement (PPIE) for diverse and marginalised groups in patient safety research and practice.

Carolyn Gamble (Greater Manchester PSTRC)

There has been substantial emphasis on the importance of Patient and Public Involvement and Engagement (PPIE) with corresponding investment for research on patient/carer experiences of healthcare. PPIE has been considered a particular priority for research and practice in relation to

Patient Safety and Quality Improvement. A recent NIHR report has also highlighted recent changes associated with PPI and called for the need to go ‘the extra mile’ in enabling even greater collaboration and diversity in inclusion. It is also important to understand more about experiences of PPI that may not be easily measured, including difficult and challenging situations where current understanding is limited. There is a need for innovative qualitative research on perspectives and experiences of patient/public contributors and researchers. This is especially important for research focused on sensitive health topics and amongst marginalised groups. This PhD project will enable qualitative research to inform an understanding of the social and ethical implications and support needs for enabling high quality PPIE. I am in the first few months, where my presentation will focus on three broad areas of PPI/E, Patient safety and PPI/E as well as an overview of marginalisation.

A study exploring the experience of patients and their carers / families who make complaints about their acute mental health in patient care.

Mary Smith (Yorkshire and Humber PSTRC)

Background: Mental health services, alongside most services within the NHS, collate views and feedback from people who have accessed their services with tools such as the friends and family test or ‘choice’ web sites. This gathering of feedback is a useful tool for service improvement and for rating how services perform. Indeed regulators such as the Care Quality Commission, Health Watch and NHS Improvement publish this data on a regular basis, giving oversight of how people who use services view them. Unfortunately, despite the data collection, for mental health services this feedback remains overwhelmingly negative, with people continuing to express dissatisfaction about services that can be seen as coercive or restrictive, with ward environments that feel neither safe nor therapeutic. It seems that the system for collating feedback may have become over-burdensome, and may be seen as the end product, leaving little time for effective listening, reflection and service improvements. Further it also seems that the actual experience of providing this feedback is a little researched area, and one that if explored further may provide insight into how effective services are at listening; how effective at learning, potentially leading to recommendations for service improvements. **Aims:** This study aims to explore the individual experience of providing feedback within acute mental health inpatient settings. It is hoped that by understanding how we listen, how we respond and how we provide that response to individuals, services can better understand the effectiveness of their current listening systems, and possibly develop systems that are more responsive, more effective in both cost and time, leading to an overall improved service experience. **Methods:** The study is composed of three distinct phases, an initial systematic review of patient, carer and family experiences; a review of local and national UK themes of patient complaints and a qualitative study exploring the actual experience of making complaints about in patient care. The qualitative study will consist of semi-structured interviews across local services with two distinct groups – patients and their families and carers.

Session D

Session title: Supporting safety across time and healthcare settings.
Location: Mind (7th Floor)

The expertise of patients with chronic illness: A rapid review and conceptual framework.

Katelyn Smalley (Imperial PSTRC)

Background: A rise in the global prevalence of chronic illness has been accompanied by shifting expectations of the role of patients with those long-term conditions. Namely, that patients will be active, prudent consumers of healthcare, and that they will predominantly treat their chronic conditions at home through self-management. Self-management training programmes designed to support patients to do this have shown mixed results: while they seem to broadly improve self-confidence, self-efficacy, and quality of life, there is less evidence that they improve health outcomes, reduce healthcare utilisation, or change the way patients behave at home. In order to design programmes that better achieve the stated goals, further understanding of the following is required: 1) What are the baseline capabilities of patients? 2) Which aspects of understanding chronic illness are uniquely within the purview of patients? 3) What are the organisational and cultural constraints on further patient participation? **Methods:** This study began with a rapid review of the healthcare literature on the ‘expert patient’ and ‘patient expertise.’ From each included study, the following information was extracted: 1) the definition of patient expertise, 2) theoretical framework(s) or model(s), and 3) implications for chronic illness. Definitions were summarised and compared, theoretical foundations were coded based on academic discipline of origin, and implications for chronic illness were synthesised. The theoretical constructs were used to develop a unifying conceptual framework of patient expertise in chronic illness. **Findings:** The included studies drew from the fields of philosophy, cognitive and social psychology, and health services research in defining patient expertise. Patient expertise is comprised of competencies (knowledge and skills) that are derived through experience, and hermeneutics (sense-making) which help them craft a personal narrative to understand their experience. In a hermeneutic sense, all patients possess a level of expertise; in terms of competencies, expertise can vary by patient and can potentially be taught. Patient expertise is typically understood in contrast to clinician expertise, and is mediated by factors determined by the healthcare environment. These factors can include, for example, attitudes toward paternalism vs autonomy, and compliance vs shared decision-making. **Conclusions:** Patient expertise is rooted in the experience of illness, and results in patients interpreting their illness as an aspect of their broader lives, in addition to achieving fluency with their healthcare needs. The expertise of patients cannot be considered outside its relationship to the expertise of their clinicians, because patients’ ability to use their expertise can be either constrained or supported by healthcare professionals.

Promoting and supporting safety in the context of childhood long-term conditions.

Anna-Sophia Wawera (Greater Manchester PSTRC)

In recent years, medical advances, policy changes and a desire to reduce hospital expenditures have led to an increasing number of children with long-term conditions (LTCs) being cared for at home rather than in the hospital setting. This focus on home-care provides many benefits for children as it enables them to grow up within their family environment. However, delivering such complex care also poses considerable challenges for primary caregivers, mainly the parents, as they are faced with additional responsibilities related to the management of their child's condition. We found that to date, this development towards childhood LTC self-management has been inadequately examined in relation to patient safety. This presentation will therefore first provide an overview of the main concepts underpinning this research – childhood LTC self-management, challenges and risks associated with LTC self-management and patient safety. In addition, the development and preliminary findings of a systematic scoping review will be presented, focusing on common risk and safety concerns among different stakeholders in relation to childhood LTC self-management. Finally, the methodological approach of the remaining PhD study will be outlined briefly, which will consist of a qualitative study to further explore the perspectives of children, families and relevant healthcare professionals in relation to their experiences of LTC self-management and their individual views on risks and safety in this context.

Child and adolescent mental health epidemiology.

Lukasz Cybulski (Greater Manchester PSTRC)

Mental illnesses are among the leading causes of disability in the world. Research shows that most adult psychiatric disorders begin in childhood and adolescence. To improve patient care, it is important to understand how widespread mental illnesses are and how they themselves may increase the risk for self-harm and other adverse outcomes. Because published evidence that reports on the number of new cases of psychiatric disorders that occur yearly is out of date, it is unclear as to whether the number of young people affected by these conditions has increased in recent years. To address this gap in the evidence base, we will examine the number of new cases of mental illnesses that have occurred in the past 15 years among children and adolescents in the UK. Evidence also shows that individuals who self-harm often develop mental illnesses before they first self-harm. The association between mental illnesses, suicide and non-fatal self-harm and has not been studied among younger individuals to a great extent in the UK, nor has it focused on individuals registered with a GP. For this reason, we will study patterns of clinical consultations, prescription of drugs for treating mental illnesses, and psychiatric diagnoses that occur before individuals harm themselves. Moreover, there are no treatment guidelines for anxiety disorder among younger persons - one of the most common mental illnesses among young people. We will therefore examine how young persons are treated by their GP after they first receive a diagnosis of an anxiety disorder in the absence of treatment guidelines.

Speakers

Professor Rebecca Lawton, *Yorkshire and Humber PSTRC*

Rebecca is a Professor in Psychology of Healthcare at the University of Leeds. For the last 10 years, Rebecca has held a joint position at Bradford Institute for Health Research where she is lead for the Yorkshire Quality and Safety Research Group, a multi-disciplinary team of researchers engaged in high quality applied health research. Rebecca is Director of the NIHR Yorkshire and Humber Patient Safety Translational Research Centre. She conducts research across the entire translational pathway; leading a programme of research on evidence based transformation within the NHS as part of the Yorkshire and Humber CLAHRC and acting as academic director for the AHSN Improvement Academy in Yorkshire and Humber. Rebecca has published widely on patient safety and behaviour change and has received funding from NIHR, ESRC, MRC, DH, TSB and the Health Foundation. Her research focuses on the application of psychological theories to patient safety.

Karen Fernando, *NIHR Academy*

Karen Fernando has worked for the NIHR Academy (previously NIHR Trainees Coordinating Centre) since 2010. She currently works with the Training Leads in the NIHR Infrastructure to enhance the research training experience of NIHR Academy members based in the NIHR Biomedical Research Centres (BRCs), Collaborations for Applied Health Research and Care (CLAHRCs) and the Patient Safety Translational Research Centres (PSTRCs). Before that she was managing the NIHR post-doctoral level Fellowship award holders and funding competition. From 2009-2018 Karen worked for Elsevier in scientific publishing.

Professor Rachel Elliott, *Greater Manchester PSTRC*

I am a health economist and Fellow of the Royal Pharmaceutical Society. I completed my Harkness Fellowship at Harvard Medical School (2004-5) whilst at Manchester Pharmacy School as senior clinical lecturer (1996-2007). I was Lord Trent Professor of Medicines and Health, School of Pharmacy, University of Nottingham (2007-16). I am Professor of Health Economics at, and Deputy Director of, the Manchester Centre for Health Economics, University of Manchester, and the Deputy Director of the Manchester Clinical Trials Unit. I have secured over £24 million of grant funding. My research has informed UK policy change in the NHS, Department of Health and NICE. I have worked with Academic Health Sciences Networks to contribute health economics input for commissioning. Research themes include medicines safety and adherence, frail elderly, costing across different health and social care sectors, online and app technology to support self-management in chronic illness and mental health. I have been a member of a NICE technology appraisal committee since 2006.

Dr Caroline Sanders, *Greater Manchester PSTRC*

Caroline Sanders is a medical sociologist based in the Centre for Primary Care at the University of Manchester. She has expertise in health services research and qualitative research methods focusing on patient experience and digital health. She leads the ‘Marginalised Groups (Patients and Carers)’ research theme within the GM Patient Safety Translational Research Centre, and leads research focused on technologies, and long-term conditions in the Centre for Primary Care. She is Director for Public and Patient Involvement and Engagement (PPIE) at Health Innovation Manager, and is the PPIE lead for an NIHR Global Health Research Group focused on stroke care in India.

Professor Stephen Campbell, ***Greater Manchester PSTRC***

Stephen Campbell is Professor of Primary Care Research in the Centre for Primary Care of the School of Health Sciences at the University of Manchester, which he has worked for since 1993. He is the Director of the NIHR Greater Manchester Patient Safety Translational Research Centre (GM PSTRC). He has 250 publications and has been awarded >£21,500,000 in grant funding. His main research interests focus on the quality and safety of primary care and across transitions of care and the development and application of quality and safety measures and improvement strategies. He is the course leader for the Primary Health Care Module of the Masters in Public Health/Masters in Research and was a postgraduate research tutor from 2007-2015. He has held joint contracts in Germany, the Netherlands and several Universities in Australia.