

## Poster Abstracts

Poster will be displayed in the Exhibition Centre for the duration of the conference. There is a designated poster viewing time: Wednesday 11 September 2019 at 18:00 – 19:00. Presenter will be available during this time to discuss their work. Poster are listed in alphabetical order by first named author.

### POSTER 1

#### **Exploring Speech & Language Therapists' (SLTs') understanding of person-centred practice using appreciative inquiry**

*Came, Nia*

*(School of Social Sciences, Cardiff University)*

The involvement of patients and their families as equal partners in decisions about their own care has developed significantly over recent years. It is felt to be particularly important in the area of rehabilitation and work with individuals with communication disability. However, even though it is considered to be 'best practice' and a sign of a quality service, it is unclear whether this actually occurs in practice. The proposed study aims to explore the understanding and application of this concept by speech and language therapists within one health service, and to establish whether a gap exists between theory and practice. The project also explores how the practice in this particular service aligns with that of other SLT services across the UK. An appreciative inquiry approach will be adopted

### POSTER 2

#### **Teamwork in the nursing handover: How nurses act their roles in acute medical settings.**

*Giannopoulou, Sarra*

*(University of Salford)*

As the current social and financial state of recent years has been turbulent, it is essential to maintain care that ensures continuity, efficacy and safety. Adding to the demands of increasingly complex and technological environments that have tendencies to lead to standardised and impersonal nursing care, the expected performance of registered nurses has become a central professional and corporate issue, but the ability to gauge this performance, remains a largely subjective exercise relying on anecdotal evidence.

Nursing handover was seen as a key premise and an opportunity to explore interactions and performances within acute medical settings. The main purpose of this research is to reveal performance rituals that take place during daily nursing handovers which serve as reports of care, but also seem to enhance teamwork and staff morale. By employing a dramaturgical approach and ethnographic participant observation methods, the study aims to deconstruct the ways in which nurses work and frame their identity within busy and unpredictable environments. As one of the main concepts of the dramaturgical perspective, the analysis of the data collected is an ongoing process that employs the idea that meaning emerges through activity and interaction between human actors.

### POSTER 3

#### **Optimistic future anticipation and rational shaping of illness trajectory can be compatible: foreshadowing of restitution in the narratives of patients with amyotrophic lateral sclerosis**

*Ishijima, Kentaro*

*(Teikyo University)*

This poster aims to show that patients with chronic diseases can shape their illness trajectories rationally even if they have medically irrational and optimistic expectations for the future. Existing studies have argued that patients need to be reasonably anticipating the future, including pessimistic predictions of prognosis, to properly shape their illness trajectory and prepare for the future. However, as studies of illness narratives have shown, patients with chronic diseases may anticipate an optimistic future, such as cure or remission. In addition, appropriate management of these patients' hopes is also necessary to maintain good health professional-patient relationships. Thus, methods must be developed to enable patients to reasonably shape their illness trajectories in a way that is different from discouraging patients and giving them pessimistic expectations for the future. To fill this gap, this poster examines the following two questions by analysing the practices and narratives of patients with amyotrophic lateral sclerosis (ALS). First, do patients who appear to accept their illness and shape their trajectory rationally compromise their undesirable future entirely? Second, how can patients who have optimistic/selective future anticipation reasonably shape their illness trajectories? As a result, this poster will show that the rational shaping of an illness trajectory is viewed by patients not only as preparation for a pessimistic future, but also as resistance to an undesired future and preparation for cure. These patients' practices suggest effective ways for professionals to take advantage of patients' hopes and have patients shape the illness trajectory rationally while maintaining good relationships.

### POSTER 4

#### **Developing an instrument to assess children's capability for assent in research settings: A comparison of age groups**

*Ishiyama Izumi, Akama, K.*

*(Tokoha University)*

## Paper Abstracts

We are studying the assent process when healthy children participate in research with no invasion or intervention. Our previous studies have suggested that 5-year-old children could "express their choice." Therefore, we focused on 4 and 5-year-old children to clarify the difference of capability between the age groups in this research. In March 2019, all of 27 children participated in the research. The parents of the children had given permission. At the first interview to assess capabilities for assent, a child received explanations about the future research (the second interview of Resilience Scale) from researchers using a booklet. Confirmation questions and answers were subjected and recorded. The assessment scale had been created with reference to MacCAT-CR up to this time. Our revised scale was composed of 3 sections of "understanding and appreciation", "expressing a choice", and "reasoning and consistency". When the child gave assent to participate in the future research, he/she asked for a signature or drawing a mark on the assent form. As results, the mean required time for assent was 10.5±2.4 minutes, and all two interviews required 16.5±3.1 minutes. T-test showed no significant difference on time between two groups. In contrast, the mean scores of the scale for assent were different between two groups ( $p < 0.01$ ). Mean score was 11.9±5.2 (range: 0-22) points in 4-years, and 17.8±4.1 points in 5-years. This difference was largely due to the difference in scores of "understanding and appreciation" section ( $p < 0.01$ ). Further study is required to increase the validity of scoring and to develop an adequate assent capability scale for children.

### POSTER 5

#### Working Time Regulations of Physicians in UK and Japan

*Kaneko, Masahiko*

*(National Defense Medical College, Japan)*

Working Time Regulations 1998 were enacted in UK with the aim of developing a law in response to the European Working Time Directive. Those regulations applied to all workers, including health professionals. Various measures were implemented to reduce the working hours of physicians. Task shifting from physicians to non-medical professionals was a kind of these measures. Some of non-medical professionals obtained prescribing qualifications. In Japan, the Act on the Arrangement of Related Acts to Promote Work Style Reform was enacted in 2017 and will be applied to physicians from 2024. The act regulates that workers' general overtime hours are up to 720 hours a year. However, the government allows a part of physicians to work overtime up to 1860 hours a year after 2024 (until 2035). Japan belongs to the continent law countries while UK belongs to the common law countries. A comparative research on task shifting from physicians to nurses shows that the task shifting extent is lower in continent law countries (Germany, Austria etc.) than in common law countries (UK, USA etc.). The introduction of measures to reduce working hours per physician other than the task shifting, for example the increase of physicians, is needed in Japan.

### POSTER 6

#### Relationships of Genetic Risk and Responsibility: A Qualitative Analysis of Narratives regarding Carriers with Spinal Bulbar Muscular Atrophy (SBMA)

*Kiya, Yukitaka*

*(University of Tokyo)*

Identifying the optimal means of evaluating genetic risk is an important concern for our society. 'Genetically risky individuals' act according to their sense of genetic responsibility (Rose 2007). However, some people with a genetic risk do not experience this sense of responsibility in the same way or at all (McConkie-Rosell et al 2008; von der Lippe et al 2017). Thus, people do not immediately act according to their genetic risk. What causes these differences in their behaviour? To understand the above, it seems necessary to investigate the conditions that induce genetic responsibility. This study clarifies one part of this issue by focusing on the carriers of genetic risk. This study examines the perception of genetic risk by comparing the narratives of two carriers of SBMA who hold starkly contrasting views on genetic risk and clarifies the differences between those that are linked to genetic responsibility and those that are not. The research was conducted using semi-structured interviews with carriers of SBMA to explore their experiences living in Japan from November 2017 to October 2018. As a result, this study reveals differences in their image of illness and related sense of time. Variation in one's sense of time as it relates to illness result in differences in a given individual's decision to act according to their sense of genetic responsibility. This study contributes by clarifying some of the conditions that induce genetic responsibility.

### POSTER 7

#### HIV, Anti-Stigma Activism and Research Ethics: Reflections from the field

*Klasto, Sini-Petriina*

*(University of Sheffield)*

This poster discusses some of the practicalities of how to conduct ethical social research among populations that experience high levels of stigmatisation due to their perceived health.

Within the OECD, South Korea has one of the highest levels of stigmatisation against people living with HIV (PLHIV). Simultaneously, South Korea lacks any comprehensive anti-discrimination legislation that could protect PLHIV from being regularly turned away from hospitals or dismissed from employment.

This raises three significant questions: What are the responsibilities of sociologists, when the potential for harm is heightened? In these circumstances, can we justify research solely on the basis of furthering scientific knowledge? How can we make sure that the generated knowledge has a positive impact on the lives of the stigmatised population?

This poster, grounded in 17 months of participatory action research with the Korean Youth PLHIV Community R, argues that furthering scientific knowledge is not a sufficient enough reason alone to conduct social research among highly stigmatised populations. Consequently, the researcher has to additionally commit to an active, practical role that seeks to improve the situation of the

stigmatised population. The poster demonstrates how this can be achieved through action research; through a simultaneous commitment to activism alongside social science. The posters illustrates how participatory action research had an immediate positive impact on Community R and how activism and social science are therefore not only compatible but desirable companions.

### POSTER 8

#### **Attempts by chronically ill people to acquire knowledge about how their bodies behave**

*Kobayashi, Michitaro, Sakai, S.*  
(Osaka Medical College)

Chronically ill people have the need to understand how their bodies behave—how they respond to specific kinds of medicine, food, or stressors. This understanding differs from conventional medical knowledge because it is about a unique body, while medical knowledge consists of probabilities statistically derived from a range of bodies. We cannot know whether this body belongs to the statistical majority or not, until it is tested in some way. This presentation contrasts the chronically ill person's knowledge with that of medical staff and explores the possibility of grasping people's experiences using the concept of an "attempt to acquire knowledge about one's body". First, the researchers examine the nature of chronically ill people's knowledge in contrast to the knowledge acquired by medical professionals from an epistemological point of view. The nature of medical knowledge has been debated extensively in the philosophy of medicine. The researchers focus on some related theoretical issues. Then, the researchers examine their interviews with chronically ill people to identify whether this theory can be applied to improve our understanding of people's actual behavior. Some of the participants reported their experiences when they stopped taking medication for a certain period. According to the researchers' understanding, refusing medication does not simply indicate laziness about adherence to the necessary therapies; it should be interpreted as an attempt to acquire knowledge about how their bodies behave when medication is discontinued..

### POSTER 9

#### **Bedside care and its consequences: an ethnography of the care people living with dementia receive in hospital wards**

*Northcott, Andy, Featherstone, K., Vougioukalou, S.*  
(De Montfort University)

The acute hospital setting is a key site of care for people living with dementia. As many as one in four hospital beds in the UK will be occupied by a person living with dementia at any given time. Despite this, people living with dementia remain a highly vulnerable group when admitted to an acute hospital ward, with higher rates of mortality both during and after an admission, higher rates of prolonged admission, delayed discharge and increased risk of functional decline.

This poster draws on the findings from two multisite ethnographic studies (NIHR HS&DR 31/10/80, 15/136/67) focussed on increasing understandings of the organisation and delivery of everyday care. Since 2016, 265 days of observations have been taken from 17 wards known to admit high numbers of people living with dementia, located within 6 hospitals across England and Wales. This fieldwork is ongoing

Everyday bedside care was highly routinized and tightly timetabled, driven by organisational goals of routine and risk reduction. Ethnographic observations identified that the delivery of care at the bedside could contribute to the production of agitation in patients living with dementia, and the production of labels and classifications that influence understandings of dementia. Ward staff had limited repertoires of talk during their interactions at the bedside and focussed on reminding people living with dementia of the 'rules of the ward'.

For people living with dementia, the failure to recognise their care needs at the bedside has myriad consequences, both medically and socially, within the ward and beyond it.

### POSTER 10

#### **Vulval skin conditions: a chronically underexplored area – a systematic review and future research questions**

*Rees, Sophie, Kirby L., Simpson, R.*  
(University of Warwick)

Several chronic skin conditions can affect the vulval area, the commonest being vulval lichen sclerosus (LS). LS causes intense itching, pain, and scarring of the skin resulting in architectural changes sometimes requiring surgery. Vulval LS has a potentially major impact on taken-for-granted everyday activities, and self-identity may be profoundly threatened, yet there has been little attention paid to the condition in both the social science and health literatures. A recent survey found that 1/5 women with a vulval condition considered suicide or self-harm as a result. Knowledge and awareness of LS and vulval disease in general is poor, and sufferers may feel marginalised and stigmatised.

In a systematic review of the literature, I could find only three publications (two studies) which explored the experience of LS from the perspective of those with the condition. This limited literature highlighted the influence of gender norms as motivation for surgery, and also that sexual dysfunction is only one dimension of the experience of LS. It also indicated women feel a sense of injustice at the limited knowledge of healthcare professionals and the few treatment options and they seek alternative and complementary treatments.

## Paper Abstracts

This poster will discuss the findings of the systematic review and outline future research questions from a sociological perspective.

### POSTER 11

#### **Ethical, legal and social issues in the investigation of the school-age children in the national birth cohort study, the Japan Environment and Children's Study (JECS).**

*Suda, Eiko*

*(National Institute for Environmental Studies)*

JECS is the Japanese national birth cohort study involving 100,000 parent-child pairs, launched in 2011 focusing on the impacts of environmental factors on children's health and development. Currently the oldest child participants (CPs) are 8 years of age, and CPs are on the way of follow-up study, collecting health outcomes and exposure measurements, which will continue until they reach 13 years of age.

The follow-up study has been conducted mainly by semi-annual questionnaire survey, which were filled by mothers. However, as CPs grow older, the necessity to ask CPs directly about their cooperation raised, since it is sometimes difficult for parents to comprehend the physical and mental developments of CPs who are entering puberty. JECS is planning to conduct the questionnaire survey which requires to CPs to write by themselves from 10 years old.

In the survey, some information which may relevant to CPs quality of life might appear, such as difficulties in the school life or human relationship, physical matters, undesirable lifestyle habits including drinking, smoking and drug intake, and so on. In such situation, we will face to the dilemma between parent's right to know and CP's right to hide. We will promise to CPs to keep their answers secrets, but we also have the obligation to consider CPs welfare including their parental care.

The discussions on such issues in our ethics committee by experts in law, sociology, school health, and so on, will be presented. And our experiences in the pilot study will be also presented.

### POSTER 12

#### **Treatment pathways and decision making in sleep disordered breathing in children**

*Watson, Rose, Powell S., Highton, C.*

*(Northumbria University)*

##### Background

Paediatric sleep disordered breathing (PSDB) is a spectrum from simple snoring to partial airway obstruction (obstructive sleep apnoea (OSA)). In the UK 12% of 4-5 year olds snore and up to 2% have OSA[1, 2]. OSA can be caused by large adenoids and tonsils; the most common treatment is adenotonsillectomy, with around 16000 annual paediatric tonsillectomies in England in 2016[3]. There are variations in surgery rates in the UK[4], with limited exploration of treatment pathways.

##### Methods

Semi-structured qualitative interviews with five General Practitioners (GPs); six Hospital Doctors (HDs); and 11 parents of children aged 3-9 referred to Ear, Nose and Throat (ENT) clinics.

##### Findings

Some parents felt concerns were not taken seriously by GPs and had several appointments before referral to ENT. GPs reported little knowledge of PSDB, some could not easily think of any cases. They suggested awareness raising of PSDB symptoms in children would be useful.

Parents were not always aware of related symptoms, particularly if referred to ENT for other issues, such as hearing problems. All parents in our study were satisfied with recommendations of ENT Consultants and did not report particular reluctance for their child to undergo surgery if deemed necessary; where surgery was not recommended parents felt this was valid.

ENT Consultants were very knowledgeable, unsurprisingly, about relevant symptoms to ask parents about relating to PSDB in specific age categories.

##### Conclusion

Further work to raise awareness of this kind of information may lead to more consistent referral rates via GPs.