Poster Presentations

Posters will be displayed in the Hamish Wood Building reception area for the duration of the conference. There is a designated poster viewing time: Wednesday 12 September 2018 18:00 – 19:00. Presenters will be available during this time to discuss their work. Posters are listed in alphabetical order by first named author. Alongside the poster session we are pleased to announce there will be a drinks reception kindly hosted by the Sociology of Health and Illness.

SOCIology OF HEALTH & ILLNESS

Poster Presentation Prize

Please don’t forget to vote for the best poster – each poster has been allocated a number, please refer to this number when completing your ballot slip. You will find the ballot slips at conference registration, the ballot will be placed near to the poster display area. Voting will close at 18:15 on Thursday 13 September, and the winning poster will be announced at the conference dinner. The winner will receive £100 worth of SAGE book vouchers.

POSTER 1

Parents’ Constructions of Childhood and Parenthood When a Child has Cancer: A Qualitative Analysis of Online Narratives

Burles, Meridith, Bally, J.
(University of Saskatchewan)

The diagnosis of childhood cancer can introduce an array of complex emotions into family life, as well as disruptions to past routines and functioning. Parents often struggle with fear and uncertainty related to their child's illness and possible health-related outcomes. While some parents find it difficult to communicate about their worries, others take solace in documenting and communicating about their experiences on the Internet via blogs, social media, and personal stories shared on organizational websites. These online narratives offer rich insight into family experiences when a child has cancer and the ways in which parents construct and given meaning to their circumstances. This presentation will describe findings from a qualitative study of publicly available online narratives produced by Canadian parents of children with cancer. Narrative analysis revealed parents' awareness that childhood cancer diverges from dominant socio-cultural constructions of the life course and their ensuing efforts to find meaning in their child's potentially shortened life. In this presentation, parents' constructions of childhood cancer and associated meanings will be examined through a sociological lens that incorporates theories of the life course and childhood. In addition, parents' understandings of the caregiving role will be explored to illuminate how they manage the threat of cancer to their child's well-being relative to constructions of parenthood.

POSTER 2

A Proactive Recruitment Approach for Inviting Residents from Disadvantaged Neighbourhoods to a Health Intervention - Why, When and For Whom Does it Work?

Bysted, Sofie, Overgaard, C., Bøggild, H.
(Aalborg University)

Title: Using proactive recruitment to reach low-SES neighborhood populations. A qualitative evaluation of inviting residents to participate in a community-based health intervention.

Background: People living in low-SES neighbourhoods participate less in health interventions compared to groups in a more prosperous socioeconomic position. Active recruitment strategies are found to increase the participation rate. However, why and under what circumstances divergent recruitment approaches work, require further investigation. In Aalborg, Denmark, health professionals employed by the municipality perform proactive recruitment ringing doorbells in low-SES neighbourhoods. They ask residents how they are doing and invite them to participate in health-related activities available in their local area.

Aim: Assessing why and under what circumstances this proactive recruitment strategy applied in Aalborg can promote participation amongst low-SES groups. It is examined, what the proactive meeting immediately entails for residents, which groups are recruited for activities and how residents' experience being contacted by a health professional this way.
Paper Sessions

Design: The realistic evaluation design, which aims at addressing: what works – for whom – under what circumstances and why? A program theory explaining assumptions about how this recruitment approach works is tested.

Methods: How three different health professionals in three divergent neighbourhoods implement the proactive recruitment approach are investigated by interviews with the professionals and direct observations during the recruitment. An adjusted version of the realist interview is used for interviewing residents having met the health professionals in the recruitment process.

Results: This study is being conducted from April-July; results will be presented at the conference

POSTER 3

Beyond the Bespoke –Can the Hands of X Model of Co-Design for Prosthetic Limbs be Applied Within the Context of the NHS?

Gooding, Jo
(Kingston School of Art)

Hands of X was an RCUK-funded research project led by designers at DCJAD, University of Dundee. It produced a collection of prosthetic hands featuring a palette of everyday materials, demonstrated co-design between the wearers and makers, and offered patients an experience that facilitated engagement and choice in limb selection. There is a culturally-constructed social stigma associated with many medical appliances and assistive technology. The interactions between clinicians, patients, designers and creators can be pivotal in influencing the reception and use-value of medical aids. Design-thinking approaches can have a role to play in addressing, and hence improving, the experiences of patients.

The project produced prosthetics and prototyped the user experience of the service. Patients were offered consultations in a bespoke fashion environment rather than a clinical transaction in a medical setting.

The innovations of the project have received academic and design recognition; examples of the prototype hands feature in the exhibition Access+ Ability at the Cooper-Hewitt Design museum in New York; and the team received a Stephen Fry award for public engagement with research.

At its 70th Anniversary, the NHS is reflecting on how it can support patient-focused innovations. This 'Design for Health Interactions' fellowship asks the questions: Can the Hands of X model of co-design for prosthetic limbs be applied within the context of the NHS? What are the considerations and challenges that need to be overcome?

This poster will present the initial findings of this scoping project and invite reflection and insights from conference delegates.

POSTER 4

Parent and Health Professionals' Experiences of iuMRI in Prenatal Diagnosis for Fetal Brain Anomaly

Graham, Ruth, Lie, M., Robson S., Griffiths, P.
(Newcastle University)

Prenatal diagnosis (PND) technologies have attracted social science much critical attention, in part because PND offers rich case studies of intrinsic interest, which can be used to reflect on ethical, legal and social dilemmas in health care provision. However, as Williams (2005) notes, such reflections are often retrospective in fetal medicine, after care pathways have developed. This sociological study of parent and professional experiences of iuMRI in PND was nested within a clinical trial aiming to assess the diagnostic accuracy of iuMRI in developmental brain anomalies (MERIDIAN). It offers the opportunity to consider not only what the iuMRI technology does, but also how professionals and parents use it to transform their experiences of diagnostic and prognostic uncertainty into more imaginable possibilities. Our analysis provides insight into parents’ and professionals’ perceptions of encountering the iuMRI technology, and its broader acceptability for use in antenatal health care. We combine the perspectives of both professionals and patients as stakeholders in a context of ongoing development of iuMRI provision in the UK, and identify three dominant themes in participants' accounts of using iuMRI in PND for brain anomaly. These three themes - (1) Accessibility; (2) Triangulation; and (3) Quality Assurance – demonstrate the centrality of a collaborative community of understanding for those who use iuMRI, and the active, embodied role that pregnant women contribute to the PND process. Whilst the iuMRI technology is a significant player in this area of policy development, so too are the people who accomplish this form of health care.

POSTER 5

The Current Sociological Status of Family Medical History in the UK and Japan

Iida, Hiroshi, Iida, H., Muto, K.
(The university of Tokyo)

Family medical history (FMH) provides clues to the predisposition to illnesses and may highlight specific concerns that a patient may have about a certain disease. However, previous studies on the prevalence and extent of genetic discrimination have only described that people experience genetic discrimination based on family history. Several papers note that the definition of 'genetic discrimination' include being treated unfairly because of FMH (Bombard et al. 2009; Joly et al. 2013). In the US, the Genetic Information
Nondiscrimination Act (GINA) of 2008 legally protects individuals against genetic discrimination on the basis of genetic information in health insurance and employment, including FMH. Both the UK and Japan have no legislation to ban genetic discrimination in insurance and employment based on an individual's FMH and genetic test results. In the UK, life insurance companies can request that applicants declare their FMH when issuing their applications, while Japanese life insurance companies stopped collecting FMH from applicants more than forty years ago due to it being useless for precise assessment. Compared to genetic test results or genomic data, the appropriate protection and use of FMH has not been discussed. We explore the current sociological status of FMH both in the context of genetic discrimination and the protection of personal information in the UK and Japan.

POSTER 6
Exploring a Methodology for Interrogating Abortion Stigma
Maxwell, Karen, Purcell, C., Hoggart, L., Bloomer, F., Rowlands, S.
(University of Glasgow)

A growing literature has examined abortion stigma, primarily in the US context, highlighting its grounding in health inequalities which are predicated on rigid understandings of female sexuality. Despite a body of recent work examining abortion, manifestations of abortion stigma in the UK remain poorly understood. Given that stigma is highly socio-culturally specific, UK-focused investigation of this phenomenon has potentially significant implications for equitable access to reproductive healthcare.

This paper explores methodological issues from the SASS (Sexuality and Abortion Stigma: Secondary analysis) Project. This interdisciplinary, Wellcome Trust-funded study is designed to explore: how abortion stigma is constituted in the UK; the common assumptions about female sexuality which frame abortion narratives; how abortion stigma is resisted and perpetuated; and how abortion and other sociocultural narratives might converge or differ across the UK's various jurisdictions. To do so, ongoing qualitative secondary analysis (QSA) is incorporating accounts from a broad range of groups including women who have sought treatment, health professionals, educators, young people, and trade union members.

The paper explores the potential of a qualitative secondary analysis (QSA) methodology to facilitate interrogation of existing data on abortion, where original sources of data vary in focus and format. The paper thus builds on learning from previous QSA studies, to explore the specific advantages and challenges in conducting secondary analysis of data on a potentially sensitive topic. In so doing, it contributes to the body of knowledge on implementing QSA, and on the applicability of existing conceptualisations of abortion stigma to the UK context(s).

POSTER 7
Illness Accountability: Why must Sufferers of ME/CFS and FM Account for Their Illness?
Nojima, Natsuko
( Osaka University)

Contested illnesses such as ME/CFS and FM are medically suspect since they have not yet been defined and recognized as actual diseases. Even though the perception of these illnesses has changed in some countries, the symptoms and problems of patients suffering from these illnesses still tend to be trivialized.

Drawing on interviews with ME/CFS and FM patients, this study examines when, how, and why such patients account for their illness to others. In both the intimate and public spheres, these patients often must explain their illness in order to be exempted from their normal duties, to be understood in their suffering, or to receive disability pensions. In many cases, patient explanations are dismissed as lacking legitimacy and arouse suspicions of the patient's motives. Although sufferers may describe their condition in detail using the latest medical facts, there remains a contemporary quandary: When the medical facts are not biomarkers, they may explain the condition, but they cannot explain the causation.

Unlike cancer or diabetes, it is the salient feature of contested illnesses that patients must account for their illness again and again. This study suggests that a description of the condition is not considered sufficient to fulfill the requirement of accountability in the case of contested illnesses, and that without biomarkers or proof of causation by biomedicine, it is inevitable that patients run into an impasse.

POSTER 8
Outcomes of Patients’ Evidence with Novel, Do-It-Yourself Artificial Pancreas Technology (OPEN)
O'Donnell, Shane, Raile, K., Braune, K., Cleal, B., Kechadi, T., Doyle, G., Willeaing, I., Skinner, T., Lewis, D., Tappe, A.
( Insight Centre for Data Analytics)

Patient-led or 'do-it-yourself' approaches to technology-enabled solutions for chronic conditions such as type 1 diabetes mellitus (T1DM) has become an increasingly common phenomenon in recent years and is currently a ‘hot topic’ amongst healthcare professionals, industry and patients themselves.

A key example is the growing movement of those living with T1DM who are choosing to build Do-it-Yourself artificial pancreas systems (DIYAPS) with the support of open source guidelines developed by a group of core patient innovators (https://openaps.org/). There
is prima facie evidence to suggest that these systems are more advanced, sophisticated and safe than anything currently commercially available to patients. Despite this, there has been a paucity of academic research carried out to-date on DIY closed-loop technology and its end users.

This project brings together an international and intersectoral network of technologists, clinicians, social scientists, patient innovators and advocates to develop an evidence-base surrounding the impact of DIYAPS on those living with T1DM as well as current chronic care models more generally.

Utilizing a realist evaluative framework and mixed methods approach, this project will examine the key clinical and quality of life outcomes of DIYAPS end-users. Secondly, it will examine potential barriers to scale and, in particular, the health equity implications associated with socioeconomic, gendered, ethnic and age-related differences in access to technologies needed to build such systems. A critical component of this research is patient/public involvement and all aspects of project development are led by researchers who live with T1DM.

POSTER 9
Electronic Patient Records and the Shaping of Clinical Hospital Work
Reay, Victoria, Lisa Wood, Liz Brewster
(Lancaster University)

Medicine as a practice has been adjusting and adapting to technologies for hundreds of years. From the stethoscope to the microscope, each has led to changes in the way medicine is carried out. The formation of the medical record has been part of that evolution; with the note growing from a doctor's personal archive, to a multidisciplinary institution-held file. Electronic patient records (EPRs) are now starting to replace paper medical notes in hospitals across the UK. EPRs promised increased accessibility, legibility, safety, and efficiency, but despite costly national programmes, adoption of the EPR in hospitals, as a replacement for paper, has been slow. Research has shown that removal of the paper record as a central communication and collaboration device appears to be having effects on the way that clinicians work together. My project will be based on a medical ward, observing the use of the EPR enacted through a computer on wheels. Ethnographic research methods will be used in conjunction with Actor Network Theory to answer how the relocation of information, from paper to computer, is changing the ways that medicine is practiced.

POSTER 10
Disclosure of Hereditary Cancer Risk Within Families: Cancer Patients’ and Families’ Attitudes and Experiences in Japan
Ri, Izen., Ri, I., Nagai, A., Muto, K.
(University of Tokyo)

Since the 2010s, professionals have increasingly encouraged patients to share medically ‘actionable’ information, such as hereditary cancer risk, with family members for early disease detection and prevention. Cancer patients who undergo tumour profiling tests may reveal incidental/secondary findings, such as BRCA1/2, which is an ‘actionable’ gene predisposing to hereditary breast and ovarian cancer (HBOC), to at-risk relatives.

Despite several empirical studies about familial communication (Forrest-Keenan et al. 2003; 2005) and preference regarding incidental genomic findings discovered during tumour profiling (Yushak et al. 2016), little has been revealed in Japan. This study explored cancer patients’ and families' willingness to share hereditary cancer risks and HBOC patients' and their families' experiences of familial disclosure.

Anonymous online surveys were administered to 2661 cancer patients and family members of patients aged 20–79 years in March 2018. Of 1761 respondents, 927 cancer patients and 834 family members responded (response rate, 66.2%). HBOC patients and their families were recruited for in-depth qualitative interviews; 6 female patients, 2 genetic relatives, and 1 male partner participated from January to March 2018.

In total, 68.7% of cancer patients preferred to share hereditary cancer risk information with their families, and 82.4% of family members preferred to receive such information from patients. However, our interview suggested that although many HBOC patients felt responsible for sharing genetic test results, relatives' understanding of medical or genetic information influenced who the patients confided in. This paper explores cancer patients’ attitudes towards genetic testing and scope of familial disclosure in the genomic era.
POSTER 11

Experiencing and Making Sense of Suffering in Palliative Care Work

Richardson, Natalie
(University of Sheffield)

Suffering is an emerging field of sociological thought. Much has been written about how suffering is experienced by chronically or terminally ill individuals, refugees and people living in poverty. In this, we understand that suffering often involves a renegotiation, or a loss, of personhood. However, little is known about the caregiver's perspective and their own understandings of witnessed patient suffering. This presentation draws on the early findings of an ethnographic research project currently being conducted over 6 months in a hospice located in the North of England. The work seeks to explore the day-to-day experiences of palliative care workers, who attempt to lessen or alleviate the suffering of terminally ill patients on a daily basis. More specifically, the study looks to appreciate the social relationships, interactions and engagements between palliative care workers and their patients. Beyond the emotional labour rhetoric, significant and important relationships exist within hospices, between carers and their patients, which are mostly saturated with intense human suffering. This research seeks to explore the ways in which suffering is made sense of when it is witnessed on an almost daily basis by professionals. In doing so, the study hopes to provide an alternative contribution to the sociology of suffering by examining the ways in which the caregiving palliative professional experiences suffering within their place of work.

POSTER 12

The Ethics and Politics of Sharing Stories For Patient and Public Involvement

Sanders, Caroline
(University of Manchester)

Doing qualitative research about experiences of health and health care often entails research participants telling their personal stories of such experiences. Feminist researchers have long drawn attention to the 'ethics and politics' of in-depth interviewing pointing to the exploitative potential, power dynamics and inequalities in such research. Others have also reflected on the ethical issues associated with researching sensitive topics for researchers (interviewers), and research participants (those being interviewed). Increasingly, public involvement in such research also means that patient and public involvement (PPI) partners share their own stories of experience, as well as working with researchers to analyse data. Many research projects using these methods can involve collecting and sharing sensitive and sometimes upsetting stories. New collaborations established through PPI are very different to the historical approach to doing research where researchers tended to work at a distance from their research participants. Putting patients and the public at the centre of our research entails relationships based on partnership between researchers and PPI contributors, and between contributors who are often working within small focused groups. This in turn may be reflected in changing features of research relationships including requirements for greater reciprocity and mutual disclosure. However, there may also be new issues regarding responsibility, ethics, and reflexivity that researchers and PPI partners may feel ill prepared for. This paper explores these issues in relation to recent research focused on the collection and use of stories of health care experience for people with long-term conditions, including severe and enduring mental health problems.

POSTER 13

Sawitri, Ni Komang Ari, Cuthill, F., Kean, S.
(The University Of Edinburgh)

Hypertension is widely understood to be a lifestyle disease that is most commonly experienced in adulthood. In contrast to European countries, where the management of hypertension is framed within an individual behavioral context, the everyday management in Asian countries inevitably involves the partner, children or grandchildren. In this context, the family members' perspectives and direct care practices require exploration.

The study aims to explore the family's experiences in controlling hypertension in Denpasar, Indonesia. It shows that the control of hypertension in daily family life can result in conflict between family members, for instance between the need to control daily food intake and personal food preferences. Other sources of conflict may be the need for families to face their responsibility to society, for example, Balinese female patients forgo attending weekly exercise class because they were expected to fulfill their responsibilities in preparing banten (the offerings) at their temple. The concept of 'family negotiation' has emerged as a key aspect of hypertension management within intergenerational families in Bali. Negotiations are influenced by the family's perceptions and knowledge about hypertension, the socio-cultural-economic aspects, and emotions. Theoretically, these 'family negotiations' are situated within the System Theory (Broderick, 1993, Bertalanffy, 1968) where the family is understood as interrelated, dynamic, and complex.

Individualised self-management health improvement models, as promoted by the Indonesia government, are not necessarily the most appropriate for an Indonesian context where family plays a critical role in the control of hypertension.
POSTER 14

Are differences in physical activity across socioeconomic groups dependent on which physical activity variables are studied?

Stalsberg, Ragna, Arve Vorland Pedersen
(Norwegian University of Science and Technology)

In recent years, the assumption that individuals of higher socioeconomic status (SES) are more physically active than their lower SES counterparts has been challenged by findings that differences across groups might be related to which physical activity (PA) domains have been studied. Many studies may have concluded on the relationship without accounting sufficiently for the total amount of PA. The present review identified relevant studies in the MEDLINE, ISI Web of Knowledge and SPORTDiscus databases using the search terms: ‘socioeconomic’, ‘socio-economic’, ‘socio economic’ and ‘social class’ to meet all variations of the variable ‘socioeconomic status’ in combination with the term ‘physical activity’. Only studies applying the dimensions of intensity, frequency, type/mode and duration in measuring PA were included in order to secure a more homogenous sample. From the near 3400 titles and abstracts examined, fifty-six studies met the inclusion criteria and were included in the sample. These were subsequently split into four PA domains; transport PA (TPA), occupational PA (OPA), housing PA (HPA) and leisure time PA (LTPA). The assumption of a higher PA-level in the high-SES group held only for LTPA, whereas the relationship was non-existent or even opposite for all other domains. In conclusion, the assumed positive relationship between SES and PA is mainly a relationship between LTPA and SES. It is further suggested that the undue focus on LTPA paints an unrepresentative picture of the low-SES group, and that studies should account for all PA domains when studying said relationships.

POSTER 15

Japanese Patients’ Motivations for Participating in iPsc Studies: Is it ‘Biological Citizenship’ Or Something Else?

Sugawara, Fuga, Kaori Muto
(The University of Tokyo)

A Japanese stem cell scientist, Professor Shinya Yamanaka of Kyoto University, successfully established human induced pluripotent stem cells (iPSCs) in 2006. This discovery attracted enormous media attention in Japan because iPSCs were generated directly from the somatic cells of patients and did not require human embryos (Takahashi and Yamanaka 2006). For people living with chronic and rare diseases, this news strengthened both the formal and informal alliance between patients and researchers and also stimulated the interest of patients in cooperating with scientists as research participants. Among several fields, we especially focus on research on ‘disease-specific iPSCs’, which show the most potential as promising research tools for basic stem cell research. However, what motivates patients to participate in research on iPSCs? Does a ‘therapeutic misconception’ (Appelbaum 1982) occur because patients and family members fail to appreciate the distinction between basic research and clinical trials? To understand the attitudes of Japanese patients towards research and to analyze the relationship between patients and scientists, we draw on the concept of 'Biological Citizenship' (Petryna 2002, Rose and Novas 2004) and 'Sociology of Expectation' (Brown and Michael 2003). We present the results obtained from a web-based, self-administered questionnaire for patient advocacy groups as well as semi-structured interviews with patients and stem cell scientists. We analyze the reasons why Japanese patients want to be involved in research on iPSCs.

POSTER 16

The Social Background of Finnish Mentally Disordered Offenders Detained in Forensic Mental Health Units

Törölä, Miisa
(University of Eastern Finland)

In Finland, scientific knowledge of people detained in forensic mental health units is been accumulated predominantly from the biomedical approach. In general, forensic mental health research discusses about individual level (e.g. genetic or neurological) factors of violent behavior, psychopathology, or substance abuse. There is apparent lack of sociological approach in this field of research, and therefore lack of understanding of effects of social background and prolonged social disadvantage on the life courses of mentally disordered offenders.

The aim of my ongoing thesis is to explore social process, which outcome is status of forensic psychiatric patient in Finnish context. Drawing on empirical data consisting of the reports of the mental state examination, the records of the previous psychiatric hospital treatment, extracts from the criminal records, and the records of the previous terms of punishment, my analysis indicates three separate groups of patients with different institutional profiles and social networks.

In this paper, I present the main findings of my research and discuss the practical implications to the practices of the social work and on treatment modalities in forensic mental health units.
POSTER 17

Evaluating the Social and Emotional Education and Development (‘SEED’) Programme in Primary Schools: More than an Event Within a System?

Wight, Daniel, Sarah Tweedie, Lawrie Elliott, Marion Henderson  
(MRC/CSO Social and Public Health Sciences Unit)

Background - Research suggests that improved social and emotional wellbeing (SEW) in primary school benefits health and academic outcomes, but it is unclear how this can be achieved. This paper will describe the co-produced SEED Programme, its evaluation through an RCT, and preliminary findings from the process evaluation.

The SEED Programme aims to improve pupils' SEW through a cycle of:

1) assessment of school needs through staff, pupil and parent questionnaires;
2) feedback to school staff and reflexive discussion leading to school-appropriate, evidence-based actions at both class and whole school level;
3) implementation and maintenance of initiatives.

A five year RCT involving 37 Scottish primary schools is complemented by process and economic evaluations.

Findings - SEED was welcomed by most schools, delivered largely as intended, and enabled staff to reflect on pupils' and teachers' SEW needs and foster a collective commitment to tackle them. It was less successful in tailoring initiatives to school-specific needs. However, the wider education system already had guidelines and policies at both national and local authority levels to encouraged schools to promote SEW. Conversely, the system also constrained schools' abilities to fully implement this radical new programme, in terms of inflexible timetabling, the need for very long term planning, and competing priorities. Consequently the control and intervention arms differed little in their adoption of SEW initiatives.

Conclusion - The trial outcomes will show whether the intervention was a sufficiently distinct 'event' in the wider educational system (Hawe et al. 2009) for its effects to be detected.

POSTER 18

Capturing the Patient Experience in Acute Care Settings: Making Sense of the Data or Making Data of the Sense?

Yiallouros, Jennifer, Bion, J., Brookes, O., Willars, J., Tarrant, C.  
(University of Leicester)

Patient experience is identified by NHS England as a key component in improving care quality. Although several indicators have been developed to measure patient experience and provide institutional benchmarks, comparatively little is known about the range of sources of information about patient experience within healthcare, or about how staff interpret and use experiential data to enhance knowledge and improve care.

We conducted ethnographic observations and interviews with a purposive sample of healthcare staff in Intensive Care Units and Acute Medical Units in three NHS hospital sites, involving around 116 hours of observations and 36 interviews.

We identified a spectrum of types of information about patient experience, including written feedback from surveys and complaints; 'bedside' conversations or patients returning to speak about their experiences; and information received in a sensory way such as a hug, or gifts of chocolates or flowers. Some types of data were codified and used as intelligence within organisations to monitor and improve services, but much of the information about patient experience remained 'below the line': it was recognised by staff and used to shape their practice informally, but never entered the formal economy of data for improvement.

We suggest that, rather than trying to convert this 'soft' information into hard data that can be counted at an organisational level, there is value in recognising the different ways in which different types of information about the patient experience can be harnessed to drive improvement. Soft data can promote grass-roots improvement through reinforcing good practice and facilitating reflection.