



King's Research Portal

Document Version
Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Donetto, S., Desai, A., Zoccatelli, G., Allen, D., Brearley, S., Rafferty, A. M., & Robert, G. (2021). Patient experience data as enacted: sociomaterial perspectives and 'singular-multiples' in healthcare quality improvement research. *Sociology of Health and Illness*.

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Patient experience data as enacted: sociomaterial perspectives and ‘singular-multiples’ in healthcare quality improvement research

Abstract: Over the last three decades, sociomaterial approaches to the study of healthcare practices have made an important contribution to the sociology of healthcare. Significant attention has been paid to the role of technology and artefacts in healthcare and the operation of actor-networks but less space has been given to questions of ontological multiplicity in healthcare practices. In this paper we draw upon our study of patient experience data in five acute hospitals in England to illustrate how treating patient experience data as ‘singular-multiples’ can enable useful insights into patient experience data work in healthcare organisations. Our data was generated during 12 months of field work at five participating hospitals and included organisational documents, field notes, informal and formal interviews with frontline and managerial staff and patient representatives at the study sites. We use the examples of the Friends & Family Test (FFT) and the National Cancer Patient Experience Survey (NCPES) in England to consider the multiple nature of data as it is enacted in practice and the work data does when coordinated as an entity in the singular. We argue that, and discuss how, the sociomaterial insights we discuss here are relevant to healthcare quality and improvement research and practice.

Word count:200.

Total word count: 8,031 (including all text except abstract and appendices)

Introduction

Over the last three decades, sociomaterial approaches to the study of healthcare systems and practices have generated useful sociologically relevant insights into the relational and emergent nature of healthcare work (e.g. Allen 2013; Berg 1997; Mol 2002; Sandelowski 2003). The body of work paying attention to the significance of materialities within the sociology of health and illness is mainly rooted in the theoretical and empirical traditions of science and technology studies (STS) (e.g. Jasanoff et al. 2001) and ‘new materialist’ approaches (Coole and Frost 2010). As Buse, Martin and Nettleton point out, this work “highlights the importance of attending to materiality and the co-constitutive role of technologies in health, yet the literature to date tends to focus on technological innovation” (2018, p.144). More specifically, whilst several studies have focused on the function of technology and artefacts in healthcare practices (e.g. Timmermans and Berg 1997; Lupton 2014; Cresswell, Worth and Sheikh 2010; Cresswell 2019), fewer analyses have interrogated “the multiplicity that makes up reality” (Michael 2017). Further, recent overviews of sociological contributions to the study of healthcare quality and safety have pointed to the potential for future sociological work to provide useful insights into the work of non-clinical roles -e.g. managers, clerical staff, cleaners, caterers and procurement specialists- to quality and safety (Allen et al. 2016).

In this paper, we draw upon our study of patient experience data in acute hospitals in England (*reference omitted*) to provide a concrete example of why it is useful to treat patient experience data work as ‘a matter of process and performance’ (Rhodes and Lancaster 2019), and how Actor-Network Theory-oriented approaches offered us a way of taking this possibility seriously.

The last decade has seen a wealth of research exploring patient experience as one of three fundamental dimensions of care quality, alongside patient safety and clinical effectiveness. With varying theoretical and methodological approaches, these research undertakings have illuminated the genealogy of concern with patient experience in the UK (Duschinsky and Paddison 2018), the several ways in which patient experience is operationalised as data (Coulter et al. 2014), the accounting processes in which it is imbricated (Pfleuger 2015), and -most recently- some of the ways in which information on patient experience may and does translate into care improvements (Sheard et al. 2017). In his study of the moderation of online patient feedback, Ziewitz (2017) problematises the taking for granted of 'experience' as "an epistemic resource that is -at least in theory- available for capture" and usually "framed as a concern with 'data' or 'knowledge' as the basis of practical action" (p.100), and offers an exploration instead of "the everyday practices that sustain [patient feedback] as a site of ordering and evaluation in its own right" (p.99). More recently, Montgomery et al. (2020) have argued for the value of understanding patient experience and patient experience data as a "relational achievement, involving the interplay of people, places and things"(p.1436) and that this relational character is too often overlooked in the healthcare research literature. In this paper we maintain a sociologically-informed focus on practices and relationships - between people, but also organisations, artefacts, technologies, policies, procedures etc. More specifically, we illustrate how treating organisations, data, interventions, and quality improvement activities not as entities pre-existing the practices that shape them in space and time, but as 'done' in and through interactions can help make sociological insights directly relevant to the applied concerns of much Improvement Studies scholarship. We do so by discussing the insights this afforded in our study. We illustrate how a focus on the socio-material nature of interactions around patient experience data in five acute National Health Service (NHS) hospitals in England allowed us to illuminate the multiple character of patient

experience data and the work data does as a ‘singular-multiple’ (Law 2004), that is as a collection of different entities that exist in their own right but are also ‘held together’ by coordination practices that make us name it as one ‘thing’ (e.g. *the FFT*).

The methodological approach we adopted for our study of patient experience data within acute healthcare organisations was grounded in Actor-Network Theory (ANT). ANT first appeared in the 1980s, in the context of sociological studies of scientific knowledge, and early ANT scholars were interested in exploring how laboratory practices operated towards the “accreditation of scientific knowledge as ‘objective’” (Michael 2017, p.11). For these scholars, the process of ‘construction’ of scientific knowledge involved humans as well as non-humans and its study required that particular attention be paid to the tools with which persuasion was achieved (as opposed to an analysis of power per se). In this sense, traditional ANT moves away from an understanding of social contexts as organised fundamentally around human agents and super-imposed structures and towards one where social contexts are studied as ‘flat’ networks of associations of ‘actants’ (Michael 2017). In our study we drew upon some key principles of ANT and the broader landscape of socio-material approaches to the study of organisational processes and healthcare practices, including the ANT-related scholarship that goes under the loose umbrella term of ‘post-ANT’ (Law and Hassard 1999; Latour 1987, 2005; Mol 2002; Allen 2013; Michael 2017). In an earlier paper (*reference omitted*), we discussed how ANT – which is best understood as a family of approaches rather than a unitary theory – enabled us to ‘take data seriously’, to pay attention to “how all things [...] become assembled and enacted in networked webs, how they associate and exercise force, and how they persist, decline and mutate” and, crucially for our purposes, to focus “not on what texts and other objects mean but on what they do” (Fenwick, Edwards and Sawchuck 2011). In particular, two aspects of ANT-informed approaches were

particularly relevant to our analysis. The first is the emphasis on how patient experience data as well as improvement are ‘enacted’ (their *performative* nature), that is how they are ‘done’ in practice. This means that our ANT-informed sensibilities enabled us to focus “on the ways in which quality improvement emerges – or fails to emerge – as a result of a contingent series of interactions between various human (individual, institutional) and non-human actors (bureaucratic documents, policies, technologies, targets, etc)”(*reference omitted*). The second aspect that was especially relevant to our analysis is the multiple nature of all reality that this performativity entails. In all ANT-derived methodological approaches, reality is understood as ‘done and enacted rather than observed’ (Mol 1999). In other words, there is no underlying reality on which we have different perspectives, but multiple realities that come into existence in interaction with variable arrays of human actors, objects and technologies. These different realities may be coherent to variable degrees and ‘held together’ by ‘coordination practices’ that may make one reality prevail over another or allow a ‘composite’ reality to emerge (Mol 2002). In this paper we provide rich descriptions from our ethnographic work and discuss two routinely collected types of patient experience data -the Friends and Family Test (FFT) and the National Cancer Patient Experience Survey (NCPES) – the former as an example of the multiplicity to which we refer, and the latter to show how patient experience data can be seen to mobilise other actors in improvement efforts.

Methods

Our study was organised in two overlapping phases. Phase 1 comprised ethnographic fieldwork at five participating NHS Hospitals. Phase 2 included six sense-making workshops (or Joint Interpretive forums, JIFs), one with representatives from all five hospitals and policymakers and five hospital-based ones. Here we focus on the findings from Phase 1 of the study. Data collection was carried out by three social scientists (AD, GZ and SD); SD and GZ

did fieldwork each at one study site; AD at two study sites; GZ and AD shared fieldwork at the fifth site.

In the UK, the Care Quality Commission (CQC) is the independent regulator of all health and social care services in England. CQC's latest available results (2014) from the annual national survey evaluation of the quality of inpatient care (Adult Inpatient Survey) guided our sampling strategy. We also took into account preliminary findings from a survey of patient experience leads from another ongoing research study (Locock et al 2020) as well as factors such as hospital size and location, staff's ability and willingness to participate, and research burden for participants. We recruited three hospitals categorised as "performing about the same as others" in the CQC classification for the 'overall views and experiences' section of the inpatient survey, and two categorised as "performing better than others". Our ethnographic observations focused on two areas of clinical care – cancer and dementia – as well as on organisation-wide patient experience data work (including both inpatient and outpatient areas). We selected dementia care and cancer care services because their similarities (high number of patients; patients can be admitted to different wards within the hospital depending on nature of acute complaint; crucial role of carers) as well as their differences (long-standing use of well-established formats for patient experience data in the area of cancer care in contrast to the challenges of documenting patient experience in the context of care for people living with dementia) would allow useful comparisons. Due to space constraints, we do not draw on these comparisons here; more detail in this respect is available in the study report (*reference omitted*). At participating hospitals, we first contacted patient experience teams, then used a snowballing approach to recruit relevant staff throughout the hospital, including ward staff and senior nurses in cancer and dementia, hospital managers, patients, patient leads and/or public governors.

Our theoretical lenses informed data generation and analysis. This means we observed data practices and discussed them with informants at length, whilst maintaining our focus on the interactions in which patient experience data became involved and the practices that these interactions appeared connected to. Our data set consisted of detailed field notes from participant observation (where participation entailed interacting with hospital staff and especially patient experience teams where present, and occasionally taking part in patient experience data work – for example, joining staff on patient experience ‘walkarounds’ or shadowing a patient experience team member administering carer survey questionnaires) and informal conversations during 116.5 days of fieldwork, transcripts from 65 semi-structured one-to-one interviews, and copies of relevant documents (for example, Board papers and Committee agendas and minutes). We provided all participants with appropriate participant information sheets; all interviewees and staff involved in individual observation were asked to sign consent forms. A breakdown of observation and interview data and key features of the participating hospitals are reported in Appendices 1 and 2, respectively. Our work was based on an analysis of field notes and transcripts, producing memos and reflective notes, and manual open coding. All study site researchers conducted case-by-case analysis and coding; cross-site analysis was conducted at study team meetings held at regular intervals which allowed for joint examination of field data.

The study was approved by the London Bridge Research Ethics Committee (IRAS ID 188882) and Health Research Authority. It was overseen by six-monthly meetings of a formal Advisory Group which included representatives from hospitals, regulatory bodies, and patient advisors

Patient experience data as ‘singular-multiple’: the many lives of the Friends & Family Test

Announced in 2012 by then Prime Minister David Cameron, implemented in 2013 and rolled out to all NHS organisations in England in 2014, the Friends & Family Test (FFT) is mandatory for all NHS acute hospitals in England. For most clinical services (maternity and paediatric services usually differ), at the time of our study the Test was based on one essential question: “How likely are you to recommend our ward to friends and family if they needed similar care or treatment?” which could be answered on a 5-point scale from ‘extremely likely’ to ‘extremely unlikely’ or by selecting ‘I don’t know’.¹ The key question is always accompanied by a free-text box for open comments and can be followed by other questions (usually to collect demographic data) at the discretion of the organisation.

In the five hospitals taking part in our study, the FFT applied to all clinical areas (with varying degrees of relevance depending on the clinical area). Four of the five hospitals used paper FFT forms and collected and processed the data in house; one hospital administered the survey via text messages, outsourcing the entire process. Our analysis of the practices through which FFT data was generated, collated, processed and circulated in the form of dashboards and reports in the participating hospitals shows how FFT was not a unitary, discrete entity endowed with stable qualities. Rather, it was multiple – its form and qualities changing constantly depending on its interactions with various human and non-human actors in the hospital.

Table 1 _ Key features of FFT at study sites

Some key FFT features at the five participating hospitals					
	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E
<i>Average number of FFT</i>	1,980	450	2,389	551	2,361

<i>responses per month (11/16-01/17)</i>					
<i>Form</i>	Paper (produced by the hospital)	Mainly card (provided by external contractor); text message in ED	Paper and online	Mainly text message	Card (provided by external contractor), kiosks, online and text messages
<i>Contractor</i>	None	Picker	None	Healthcare Communic ations	Quality Health
<i>Management software</i>	Meridian	Not known	Meridian	ENVOY	Business Objects Launchpad
<i>Discussed at Board</i>	Yes	Yes	Yes	No	Yes
<i>Used for benchmarking</i>	Yes	Yes	Yes	No	Yes

Let's consider the 'recommendation rate' (e.g. '96% of our patients would recommend this ward) of the Friends and Family Test. Recommendation rates appeared in a variety of places and interacted with a variety of 'actors' (both human and non-human) in the five hospitals we studied. For example, FFT recommendation rates always had a dedicated section in ward reports and Board papers. They also often featured on public-facing banners at the hospital reception as well as on information whiteboards for patients at the entrance of each ward. The overall usefulness of the recommendation rate was often dismissed as limited by many of our interlocutors. Some Patient Experience team members noted how its value was not univocal but was rather directly connected to another element of the FFT – i.e. the response rate. In other words, it was only when a sufficiently high response rate was obtained that a high recommendation rate was taken to indicate the overall good quality of a hospital service. As one Patient Experience team officer at one hospital put it, referring to the hospital's average

FFT responses for one month: "...if 99% of 13,000 people say they'd recommend us, we must be doing something right!" (Field notes 09/06/2017, Hospital A).

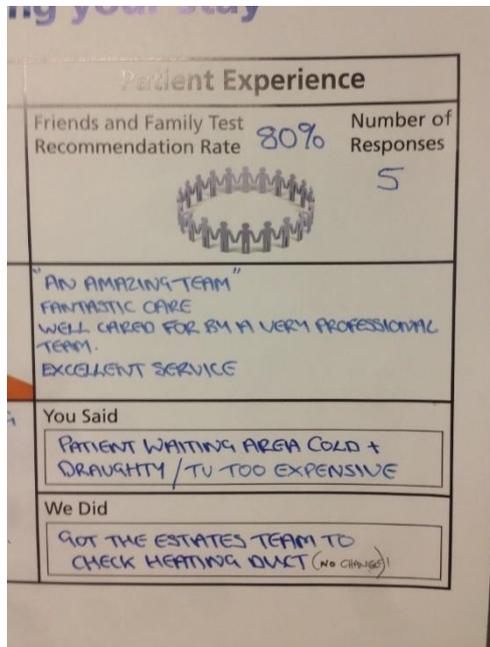


Figure 1 - Detail of ward noticeboard showing how FFT is publicly displayed (Hospital E)

The recommendation rate was also enrolled in interactions with other forms of data (e.g. other experience data such as the local bespoke survey, and/or data about safety, staffing, etc) and acquired specific meanings based on whether it showed alignment or conflict with these. At one hospital, members of staff referred to the meaningful comparison of the FFT recommendation rate with other local data as 'triangulation', whereas at another hospital staff talked of 'deep dives'. In the former (Hospital A), the FFT overall recommendation rate was looked at as one element in a complex data landscape which included, for example, the results of the National Adult Inpatient Survey or those of the local bespoke inpatient survey. In the latter (Hospital D), FFT data was included in documents and placed alongside safety or staffing data to better understand the performance of a ward or service area. In both cases, the information provided by the recommendation rate, was not deemed meaningful in itself; it was only when combined with other forms of data that the recommendation rate contributed

to generate a picture of patient experience that was valuable to the organisation. A high recommendation in the context of overall encouraging data from other data sources provided reassurance that the overall quality of care was satisfactory. Conversely, a declining FFT recommendation rate prompted staff to scrutinise other types of data – not only other patient experience data, but also safety and clinical effectiveness data, staffing data, and any other relevant information for a particular time period – to try and understand where problems might be arising.

The recommendation rate is the final output of the FFT. But, as we mentioned earlier, the FFT takes many other forms. One other example is the FFT as free-text comments. Based on our conversations with staff in clinical as well as administrative and managerial roles at our five study sites, patients' free text comments were generally considered the most useful element of the FFT. Although the anonymous nature of the Test (patients have the option to leave their contact details but rarely do so), was seen by frontline staff to make it difficult for the organisation to do something about an individual's poor experience, free-text comments still allowed for, or in some cases even demanded, intervention. This was particularly the case for negative comments. Talking about negative FFT comments, the Matron for Elderly care at Hospital E commented:

Oh you hear about them straightaway – they come flying down. But when I see three negative comments about one ward in a short space of time, I do think 'oh hang on, is something going on?' And I'll let the Deputy Director of Nursing know what we're doing about the negative comment, over the phone or at our monthly one-to-one meeting, and she'll say 'just pop what you've said to me in an email so that if anyone from the Executive asks, I've got it recorded'. (Field notes, 15/03/17 Hospital E)

Whether or not FFT free-text comments could act in this way was largely determined by how data generation was organised. The interaction of members of staff with FFT cards and the free-text comments handwritten on them is very different from the interaction with comments collected via mobile text-messaging, which are not directly handled by members of staff but require active access via some form of digital interface and to be scrutinised in bulk. At the four hospitals where the FFT was predominantly paper-based, comments were usually reviewed weekly or fortnightly by staff (typically the ward sister/manager but also members of patient experience teams). Any outstanding issue that could be addressed (e.g. a complaint about toilets cleanliness) would at that point be addressed or escalated appropriately. At Hospital E, for example, free text comments marked as 'negative' by staff transferring the information to the electronic system, were reported to the Deputy Director of Nursing who would then contact the Matron with responsibility for the ward where the comment was reported and ask them to look into it. At Hospital A, FFT cards were collected on each ward and delivered to the Patient Experience team for processing; at the point of interaction with members of this team, positive free-text comments were used to disseminate examples of good practice widely (e.g. via Twitter posts), and negative ones could prompt further action via the Divisional Director of Nursing responsible for Patient Experience and the close links she had with the team.



Figure 2 - FFT paper forms being entered in the electronic database and archived FFT cards at Hospitals A and C

The above are two examples of the transformations we observed and examined in the process of ‘following’ the life of the FFT – as well as of other technologies to collect patient experience - during our fieldwork. These examples draw attention to what we call the ‘multiplicity of FFT’. They show how ‘the FFT’ that comes to interact with a ward manager is necessarily different to ‘the FFT’ a matron comes into contact with, or a member of the Patient Experience team, or an executive director at the Board meeting and so on. In other words, when we refer to the Friends and Family Test, we are naming and thereby discursively fixing a meaning for an entity that is, in actual fact, multiple. Even though for practical purposes we call FFT a recommendation rate, a dashboard, a card with questions and comments, a report, etc – these are all different things with which different people and organisational mechanisms interact. They are not simply different ‘components’ of the test, but different entities altogether. The FFT *is* a set of rates (recommendation and response) and a trend to Board members; it *is* a pile of cards to decipher and transform into digital data and possibly urgent action for a Patient Experience team; it *is* a section of a report that is

produced monthly to matrons. This list is not exhaustive but it highlights how these ‘instances’ or ‘forms’ represent how FFT is ‘done’ differently in different sets of interactions.

Enrolling actors in improvement work: the National Cancer Patient Experience Survey (NCPES)

Patient experience data can mobilise, and be used to mobilise, key social actors in a network and to create or refashion relations, systems and infrastructure for collecting and responding to patient experience data itself. In these cases, the fact that data exists as a named, recognisable format (for example, the FFT or the National Cancer Patient Experience Survey, NCPES), i.e. the ‘singular’ in our ‘singular-multiples’ illustrated above, is important in enabling and shaping this refashioning activity. In other words, whilst the multiplicity accounts for different interactions in different networks, the fact that the multiple instantiations are ‘held together’, that they are coordinated as a singular entity also has effects, which highlights the importance of paying attention to both singularity and multiplicity at the same time. We look at some of the activities around the NCPES at one of our study sites and illustrate how the interactions this survey participates in as ‘the NCPES’ influence the relative status of other actors.

The National Cancer Patient Experience Survey is an annual survey commissioned and managed by NHS England, and designed, implemented and analysed by Quality Health, a CQC-approved national private contractor. In October each year, Quality Health contacts all acute NHS hospitals in England to obtain details of adult NHS patients with a confirmed primary diagnosis of cancer discharged from an NHS hospital after an inpatient stay or day-case attendance for cancer-related treatment in April, May and June earlier that year. In most hospitals, the Cancer Services administrative team and the Lead Cancer Nurse liaise with

Quality Health to create this list. The list of eligible patients is sent to Quality Health who construct a sample of patients to contact. The 2016 survey consisted of 59 reportable questions covering the whole patient pathway and also had free text boxes for patients to leave comments. Questionnaires were posted to the sample of patients and they were also given the option of responding online. The results of the survey are shared with hospitals approximately 12-14 months after the patients surveyed were discharged as inpatients. From observations and conversations with key staff at Cancer Services at all our study sites, it is the Lead Cancer Nurse who has responsibility for the pre-survey work outlined above and the post-survey work of reporting the data within the organisation. The results detail the hospital's score for each question; they are published on the NCPES website and are publicly available. The free-text comments are provided, organised by tumour group, privately to each hospital in a password-protected document. Clinical Nurse Specialists (CNSs) are often charged with creating action plans in response to the NCPES results for their tumour group. In some hospitals, the Lead Cancer Nurse provides guidance and oversight of action plans and/or formulates additional plans across cancer services.

The Lead Cancer Nurse at Hospital B was dissatisfied with the way in which the hospital conventionally responded or used the NCPES, which was along an action plan formulated by CNSs. She found improvement had stalled and intended to move things forward in a number of ways. We focus here on two of these: involving medical and managerial staff in addition to nurses in the organisational response to NCPES results; and involving patients to help work on the survey's findings.

Enrolling medical and managerial staff: the Cancer Delivery Group first meeting

At Hospital B, the Clinical Lead for Cancer (a physician) and other members of staff, including the Lead Cancer Nurse, had formed a ‘Cancer Delivery Group’ with the aim of better meeting national cancer performance targets. These performance targets – for example, the ‘two-week wait’ fast-track referral from GP to specialist consultation, and the 62-day cancer patient pathway (from GP referral to start of treatment) – are nationally monitored and breaches entail financial penalties. During the first meeting of this Cancer Delivery Group, the lack of a CNS in one tumour group was identified as a cause for breaches of national targets in that specialty. Later during the same meeting, the Lead Cancer Nurse presented the NCPES results and suggested that low performance in the survey in some tumour groups was the result of poor CNS staffing. The Lead Cancer Nurse asked Clinical Leads to produce action plans in consultation with their MDTs, challenging the assumption that action plans are essentially the responsibility of CNSs. A consultant agreed that CNS provide invaluable support and were the most important thing that was needed and the conversation moved onto ongoing strategies to free up CNSs’ time. An extract of our field notes from the meeting illustrate the conversation:

Leah (Cancer Services manager) is presenting the data for 62-day breaches (this is on a screen).

A consultant asks her ‘how sure are you that the data is correct?’ She replies that it is pulled from the system. A month’s data is validated the following month before it gets uploaded nationally.

Another consultant asks what has changed? He says that we were fine before and suddenly we’re in crisis – how has that happened. He seems concerned that, actually, there is no crisis at all. His explanation is that their reporting is tighter now, meaning that it looks as if there’s been a big change but there hasn’t actually been one. Leah explains

that because of the small numbers involved here, even one or two breaches are enough to tip us over into red.

[...]

Leah says that Head and Neck are suffering in particular with meeting the 62-day target because 'we don't have a CNS batting for the patients'. 'We need to be picking them up individually off the list and saying this person needs to be booked into clinic'. 'That we haven't had a CNS for seven months means that we haven't been able to do this'.

[...]

They move on to the NCPES 2016 – this is Meg's (Lead Cancer Nurse) presentation. She introduces the survey and outlines some of the areas: not enough nurses on the wards. She also says she's talking to the Academy about training to build staff confidence to have difficult conversations. Also information about chemotherapy – the satisfaction there has dropped. Some of the tumour groups which have issues – breast and gynae-oncology – we know that we have CNS staffing problems there.

She has a list of the key findings broken down by tumour group and says they will be circulated. She asks the clinicians to come up with ideas to address some of these issues. – she wants them to develop an action plan for each tumour site.

A consultant responds to what Meg is saying. 'It's the support that's given by the CNSs which can affect their experience long term. That's the most important thing that's needed [i.e. to have every patient have access to a CNS].

Meg says that where we have adequate CNS support we see good results and an absence of a CNS has a major effect on tumour groups. CNSs provide the human factor. It says to patients 'this is a friendly place'.

Meg says that they have faced recruitment issues but they've now recruited new Patient Pathway Facilitators (PPFs) to help CNSs answer telephones. And we've recruited 2

general CNSs to cover all areas where they're needed (e.g. Catherine in Derm who is a sole practitioner – to cover her when she's on leave). Meg says that the PPFs will work to free up CNS time.

That ends LM's presentation – doesn't last very long – 10 mins at the most. (Field notes 1710/17, Hospital B)

In this meeting we see patient experience data mobilised in two ways. First, the Lead Cancer Nurse built upon the link the Group had already established between lack of CNSs and lamentable performance indicators (e.g. target breaches) to link disappointing NCPES results to poor CNS staffing and enrol MDTs professionals into responding to these results by taking responsibility for action plans. Second, the patient experience data itself gained in status as a function of being associated with the discussion of breach data, which was regarded as more important and was the very reason for the constitution of the Group. In other words, the mobilisation of the NCPES through this meeting resulted in a change to the infrastructure through which it worked, as clinical staff became involved in working with it in new ways.

Enrolling external organisations and patients

At Hospital B, the Lead Cancer Nurse also worked towards involving patients in the hospital's response to the NCPES results. She organised a patient event around the survey. This was co-hosted by the regional Cancer Alliance and attended by 15 participants including patients, staff, Cancer Alliance representatives and representatives from a large national cancer-support charity (MacMillan). Cancer Alliances are collaborations set up by NHS England -and often organised by tumour group- that bring together local senior clinical and managerial leaders and practitioners representing the whole cancer patient pathway across a geographical area (<https://www.england.nhs.uk/cancer/cancer-alliances-improving-care->

locally/). The event organised by the Lead Cancer Nurse at Hospital B followed a workshop format with small-group discussions around pre-set questions and provided information about Cancer Alliance as well as the NCPES. As a result of these discussions, the Lead Cancer Nurse learned that, among other things, patients wanted CNSs to be more 'proactive' - i.e. to contact patients without necessarily being contacted by them first – and to arrange follow-up appointments within a few days from initial diagnosis in order for patients to better understand the information provided about their treatment. We also found it significant that whenever the NCPES was mentioned in terms of how it was experienced by patients, the conversations were fraught or indifferent in character. For example, one patient complained that, having completed the form online, she continued to be bombarded by paper versions in a way that left her feeling harassed and made her doubt that her online response had been properly registered. Other patients were unsure as to whether questionnaires they had responded to were in fact the NCPES or another feedback mechanism; and others still were unaware of the existence of the NCPES.

Although at this event the NCPES was ostensibly the 'headline act', we identified three ways in which it seemed to serve as an enabler for other actors to gain authority and recognition. First, by being a co-host and offering support to mitigate the shortcomings of the NCPES (for example, organising its own survey for tumour groups that were poorly served by the NCPES), the regional Cancer Alliance became an additional mechanism through which patient experience data could lead to improvement. Second, by positing the NCPES as insufficient, MacMillan gained the opportunity to propose their own patient experience work as broader in focus, and indeed proceeded to enact this alternative by soliciting patient experience feedback there and then. Third, the discussion around the NCPES mobilised a patient group providing accounts of experiences of care. By the end of the workshop this

patient group was recruited to becoming a key element of how patient experience work would be done in the future at this hospital. In effect, at this event the NCPES -understood as results, scores, benchmarking and free-text comments- provided an initial focus for discussion but quickly faded into the background, whilst relations between patients, staff, MacMillan and the Alliance took centre stage and brought about a new patient experience infrastructure which refashioned ‘doing data’ and ‘doing improvement’ at hospital B.

The two examples in this section show how, even though different workshop participants may have interacted with different versions of the survey (for example, an online or paper questionnaire in the case of patients, a report of results in the case of the Lead Cancer Nurse), it was *the* NCPES as a recognisable item that enabled the enrolment of actors for care improvement purposes. This highlights the usefulness of thinking of data in terms of singular-multiples for exploring the different networks it operates in. In the discussion below, we argue that research sensibility towards ‘singular-multiples’ as a tool-to-think-with should be cultivated further in the field of Improvement Studies.

Discussion

Despite their long history in science and technology studies (STS), sociomaterial approaches to the study of organisational processes and healthcare practices have relatively limited thrust in the healthcare quality and improvement literature. Rhodes and Lancaster (2019) critique the field of Implementation Science in particular for falling back on a realist ontology with little questioning. Their work illuminates ways in which the ‘doing’ of implementation invites us to attend to “ontological matters-of-concern” and move “from a focus on what counts as knowledge to what counts as an intervention object” (2019, p.7). It asks us to move beyond approaches that only admit “the need for social science research to explore how the

implementation of a priori evidenced interventions” is in some way shaped by the social environments - or contexts - in which these are delivered, towards ones that envisage the investigation of “how evidence and intervention, as well as their knowledge and implementation contexts, are made locally through the processes of intervention translation and implementation” (Rhodes et al., 2016, p.19). Our analysis here focuses on how patient experience data is ‘done’ in acute NHS hospitals in England and, patient experience being a key dimension of care quality, aims to be relevant to the sociology of healthcare as well as to healthcare quality and improvement research. We argue that sociological lenses that pay attention to the ways in which patient experience data work is accomplished in sociomaterial interactions open valuable avenues for improvement interventions. The ‘singular-multiple’ nature of the FFT shows us how data itself is ‘done’ in material interactions (of people with paper forms, executives with recommendation rates, computer software with transcribed comments, etc), showing us how the different instances of what we normally understand as ‘one’ survey are actually entirely different entities, entering entirely different interactions with a range of effects relevant to improvement as an organisational aim. The example of the NCPES illustrates what data that ‘hangs together’ as singular-multiple can do, what kinds of relationships it can instantiate and/or consolidate, and how it can occasion further improvement action. More specifically, we saw how, in our case, the survey was mobilised in one meeting to enrol new social actors in the generation of action plans, and in another to coordinate entities external to the service (the Cancer Alliance and the MacMillan charity) in improvement work and to enlist the input of a group of patients for improvement purposes. Like many thinkers interested in developing “new ways of understanding materiality” (e.g. Barad 1998, Butler 1990, 1993; Latour 2004a, 2004b; Law 2004; Mol 1999) have shown, paying attention to the enactment of particular realities through particular sets of interactions can “shed light on how ways of understanding material objects relate to ways of

understanding reality, and in turn to what we as a society consider politically possible” (Fraser 2020). Indeed, such a shift (even if temporary or instrumental) to an ‘ontology of becoming’ (from a more familiar ‘ontology of being’) has very practical, as well as theoretical, implications for improvement practices and organisational research.

Understanding patient experience data as non-unitary, but rather made up of multiple entities brought into existence by the practices of which they are part, is one way in which an ANT perspective affords us to think about data differently. The idea that a survey is not just one objective, stable entity that enables that collection and analysis of feedback leading to some final results to act upon, but a collection of entities which exist in their own right and take part in interactions for care improvements in different ways, shifts the focus from the final stages of the survey cycle to a range of significant interactions constituting it. This shift in focus, in turn, has two implications that illustrate the relevance of sociological insights to Improvement Studies research and practice: (1) it foregrounds the function of non-humans as well as that of humans, providing a much richer picture of the influences and relationships amenable to intervention; and (2) locates the site of possible interventions in the interactions, moving away our thinking from the ‘value’ or ‘ability’ of individuals and focusing strategic thinking on creating the conditions that allow particularly types of interactions to happen. By compelling us to attend to enactments, to how things are relational and ‘done’ in the moment (see also Montgomery et al. 2020), ANT sensibilities enable us to open up possibilities for how they might be ‘done’ differently, an endeavour of practical and political significance (in that it expands the landscape of what is possible and, with it, the opportunities to redress whose interests improvement practices serve).

In the case of the NCPES examined here, the survey served as a tool to crystallise consensus around the crucial role of CNSs and re-distribute responsibility for change across other

professional roles at a time of CNS shortage. By constituting the discussion item around which patients, staff and external agencies such as the Cancer Alliance and MacMillan can share perspectives meaningfully, it also brought new actors to commit to further action aimed at service improvement (the patients formed a group for further consultation, MacMillan offered a 'broader' patient experience angle to counteract NCPES limitations, and the Cancer Alliance proposed a new survey for specific tumour groups under-served by the NCPES). These insights help us shift the focus of any intervention from providing more or less of certain roles or entities (e.g. CNSs) to creating the organisational conditions that more easily and flexibly allow certain forms of (desirable) interactions to take place (for example, what are rapid and efficient ways of redistributing responsibilities when necessary? What agents/actors can be mobilised around a specific priority? Via which kinds of relationships?). Of course, this shift in focus has its own challenges when it comes to operationalising it in the context of quality improvement practices. However, our analysis shows that frontline staff can develop ways to facilitate the interactions that prove productive in the context of their patient experience work.

In our study, the discussion of preliminary findings with hospital staff during the sense-making workshops highlighted that the organisations were responsive to our insights and could envisage practical changes to how they operated. For example, at one study site, in response to our suggestion that acute hospitals may be able to optimise the use of patient experience data by exploring configurations of, and possible collaborations between, different professionals and teams involved at different stages of patient experience data work, staff proposed that they could do more to improve communication between managers and frontline staff in relation to patient experience data-driven changes. At another site, participants in the workshop resolved that it would be useful to organise a Nurses Day, for the patient

experience improvement work done by nurses to be formally acknowledged by colleagues and the organisation (*reference omitted*), and at yet another site, the possibility of cancer CNSs working more closely with matrons across the hospital was suggested as a strategy to improve care for cancer patients.

We do not dismiss some of the key criticisms moved to ANT and post-ANT approaches to the study of sociomateriality. We are aware that ANT-informed research has the *potential* to inadequately account for power relations; however, focusing on enactments does not mean ignoring power altogether. Rather, it entails avoiding automatically resorting to pre-existing understandings of where power lies in the organisation and focusing instead on situating power-relations as they come into being in specific interactions. We also contend that the loss of structure-agency relationships as explanatory tools is not in itself an issue: as the analysis presented here shows, a focus on the distributed agency of network interactions can offer relevant insights into how things are ‘done’ in situated practices and how they might be done differently. Lastly, we are not unfamiliar with the challenges of ontological multiplicity (see for example Michael 2017; Greenhalgh and Stones 2010) and do not claim that entertaining the possibility of foregrounding performativity and enactment of different realities (Mol 1999) is entirely unproblematic. We accept that the sort of methodological sensitivity we call for here may be disruptive (from personally challenging to ‘difficult to work with’ at organisational level), but we argue it can also be productive in very practically relevant ways, as the examples above illustrate.

We also note that other approaches to implementation and improvement practices in tune with the sensitivities we call for here (in the sense that they place as much, if not more, importance on the relationships between the components of a system as on the components

themselves) and that aim to harness the value of system unpredictability and the significance of emergent properties, do exist in the literature drawing upon complexity science (Braithwaite 2009, 2018; Greenhalgh et al. 2004; Kitson et al. 2017). However, their practical thrust in implementation and improvement work to date remains relatively limited. We argue that sociologically-informed research approaches predicated upon serious engagement with ‘singular-multiples’ and their various enactments allow for analyses that enrich current understandings of organisational practices and open up new avenues for improvement intervention. Far from being a concern relevant only to readers with an interest in the philosophy of research, attention to ontological multiplicity can be a useful tool for healthcare staff interacting directly with patient feedback in various ways as well as for managers and policymakers interested in whether and how this data has impact on care quality. In other words, interrogating the world ‘as if’ we assumed that “if reality is done, if it’s historically, culturally and materially located, then it is multiple” (Mol 1999, p.75), does not mean we must at all costs embrace a world in which any reference to pre-existing entities and categories becomes entirely meaningless. Rather, it can mean temporarily shifting perspective on what counts as ‘real’ in order to understand our actions in the world in ways we would not be able to examine otherwise.

¹ Following a recent review (DHSC 2019), the wording of this key question has changed to “Overall, how was your experience of our service?”, with options from ‘very good’ to ‘very poor’ (including ‘I don’t know’) available for ticking. Both the old and the new form have at least one free-text box for open comments.

References

- Allen D. (2013). Understanding context for quality improvement: Artefacts, affordances and socio-material infrastructure. *Health*, 17(5), 460-77.
- Allen, D., Braithwaite, J., Sandall, J., & Waring, J. (2016). Towards a sociology of healthcare safety and quality. *Sociology of Health & Illness*, 38(2), 181-197.
- Barad, K. (1998). Getting real: Technoscientific practices and the materialisation of nature. *Differences: A Journal of Feminist Cultural Studies*, 10(2), 87–128.
- Barad, K. (2003). Posthumanist performativity: Toward an understanding of how matter comes to matter. *Signs: Journal of Women in Culture And Society*, 28(3), 801–831.
- Braithwaite, J., Churrua, K., Long, J.C. et al. (2018). When complexity science meets implementation science: a theoretical and empirical analysis of systems change. *BMC Med* 16, 63, <https://doi.org/10.1186/s12916-018-1057-z>
- Braithwaite, J., Runciman, W. B., & Merry, A. F. (2009). Towards safer, better healthcare: harnessing the natural properties of complex sociotechnical systems. *BMJ Quality & Safety*, 18(1), 37-41.
- Buse, C., Martin, D., & Nettleton, S. (2018). Conceptualising ‘materialities of care’: making visible mundane material culture in health and social care contexts. *Sociology of Health & Illness*, 40(2), 243-255.
- Butler, J. (1990). *Gender trouble: Feminism and the subversion of identity*. Abingdon and New York: Routledge.
- Butler, J. (1993). *Bodies that matter: On the discursive limits of sex*. Abingdon and New York: Routledge.
- Coole, D and Frost, S. Eds. (2010) *New materialisms: ontology, agency and politics*. Durham and London: Duke University Press.

- Coulter, A., Locock, L., Ziebland, S., Calabrese, J. (2014). Collecting data on patient experience is not enough: they must be used to improve care. *BMJ: British Medical Journal*, 348: doi: 10.1136/bmj.g2225.
- Cresswell, K. (2019). Using Actor-Network Theory to Study Health Information Technology Interventions. In Scott, P., de Keizer, N., and Georgiou, A. (Eds.), *Applied Interdisciplinary Theory in Health Informatics: A Knowledge Base for Practitioners*. Amsterdam and Berlin: IOS publishers, pp.87-97.
- Cresswell, K. M., Worth, A., & Sheikh, A. (2010). Actor-Network Theory and its role in understanding the implementation of information technology developments in healthcare. *BMC medical informatics and decision making*, 10(1), 67.
- DHSC, Department of Health and Social Care (2019). NHS England and NHS Improvement guidance: Using the Friends and Family Test to improve patient experience. London: DHSC.
- Duschinsky, R., and Paddison, C. (2018). “The final arbiter of everything”: a genealogy of concern with patient experience in Britain. *Social Theory & Health*, 16(1), 94-110.
- Fenwick, T., Edwards, R., Sawchuk, P. (2011). *Emerging approaches to educational research: Tracing the socio-material*. Oxford: Routledge; 2011.
- Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. (2004). Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Quarterly*, 82, 581–629.
- Greenhalgh, T., & Stones, R. (2010). Theorising big IT programmes in healthcare: strong structuration theory meets actor-network theory. *Social science & medicine*, 70(9), 1285-1294.
- Jasanoff, S., Markle, G. E., Peterson, J. C., & Pinch, T. (Eds.). (2001). *Handbook of science and technology studies*. London: Sage publications.

- Kitson, A., Brook, A., Harvey, G., Jordan, Z., Marshall, R., O'Shea, R., Wilson, D. (2017).
Using complexity and network concepts to inform healthcare knowledge translation.
International Journal of Health Policy Management, 6, 1–13
- Latour, B. (1987). *Science in Action: How to Follow Scientists and Engineers Through Society*. Milton Keynes: Open University Press.
- Latour, B. (2004a). Why has critique run out of steam? From matters of fact to matters of concern. *Critical Inquiry*, 30(2), 225–248.
- Latour, B. (2004b). *Politics of nature: How to bring the sciences into democracy*. Cambridge: Harvard University Press.
- Latour, B. (2005). *Reassembling the social: an introduction to Actor-Network Theory*. Oxford: Oxford University Press.
- Law, J. (2004). *After method: Mess in social science research*. London: Routledge.
- Law, J., and Hassard, J. Eds.(1999). *Actor network theory and after*. Oxford: Blackwell Publishers/The Sociological Review.
- Locock, L., Graham, C., King, J., Parkin, S., Chisholm, A., Montgomery, C., et al. (2020). Understanding how front-line staff use patient experience data for service improvement: an exploratory case study evaluation. *Health Services & Delivery Research*, 8(13).
- Lupton, D. (2014). Apps as artefacts: Towards a critical perspective on mobile health and medical apps. *Societies*, 4(4), 606-622.
- Michael, M. (2016). *Actor-network theory: Trials, trails and translations*. London: Sage.
- Mol, A. (1999). Ontological politics: a word and some questions. In J. Law and J. Hassard (eds), *Actor-Network Theory and after*. Oxford and Keele: Blackwell and The Sociological Review, pp.74-89.
- Mol, A. (2002). *The body multiple: Ontology in medical practice*, Durham: Duke University Press.

- Montgomery, C. M., Chisholm, A., Parkin, S., & Locock, L. (2020). Wild data: how front-line hospital staff make sense of patients' experiences. *Sociology of Health & Illness*, 42(6), 1424–1440.
- Pflueger, D. (2015). Accounting for quality: On the relationship between accounting and quality improvement in healthcare. *BMC Health Services Research*, 15(178). DOI 10.1186/s12913-015-0769-4
- Rhodes, T., Closson, E. F., Papparini, S., Guise, A., & Strathdee, S. (2016). Towards “evidence-making intervention” approaches in the social science of implementation science: the making of methadone in East Africa. *International Journal of Drug Policy*, 30, 17-26.
- Rhodes, T., & Lancaster, K. (2019). Evidence-making interventions in health: A conceptual framing. *Social Science & Medicine*, 238, 112488, doi.org/10.1016/j.socscimed.2019.112488
- Sheard, L., Marsh, C., O'Hara, J., Armitage, G., Wright, J., & Lawton, R. (2017). The patient feedback response framework—understanding why UK hospital staff find it difficult to make improvements based on patient feedback: a qualitative study. *Social Science & Medicine*, 178, 19-27.
- Timmermans, S., & Berg, M. (1997). Standardization in action: achieving local universality through medical protocols. *Social studies of science*, 27(2), 273-305.
- Ziewitz, M. (2017). Experience in action: Moderating care in web-based patient feedback. *Social Science & Medicine*, 175, 99-108.

Appendix 1. *Summary of fieldwork and interviews*

	Visits (number of field trips)	Days of fieldwork	Interviews
Hospital A	24	25	12
			9 staff 3 patients/carers and/or governors
Hospital B	9	20	12
			10 staff 2 patients/carers and/or governors
Hospital C	7	27.5	15
			13 staff 2 patients/carers and/or governors
Hospital D	11	24	11
			10 staff 1 patient/carer and/or governor
Hospital E	6	20	15
			11 staff 4 patients/carers and/or governors

Appendix 2 - Key features of the five participating acute NHS hospitals

	Key features of the five study hospitals				
	Hospital A	Hospital B	Hospital C	Hospital D	Hospital E
Approximate number of beds and staff	<u>Beds:</u> 750 <u>Staff:</u> 5000	<u>Beds:</u> 450 <u>Staff:</u> 4500	<u>Beds:</u> 1000 <u>Staff:</u> 7100	<u>Beds:</u> 950 <u>Staff:</u> 7000	<u>Beds:</u> 2300 <u>Staff:</u> 14500
Formally designated 'Patient Experience' team	Yes 2 patient experience facilitators 1 data entry analyst	No PALS staff carries out some patient experience functions	Yes 1 patient experience manager 1 complaints and PALS manager 6 patient experience staff members 4 PALS officers 2 formal complaints officers	No A team of professionals at corporate level (i.e. Lead Nurse for Corporate Services, Corporate Matron, Quality Improvement Team, Assistant Director of Service User Experience) overviews the integration of patient experience work in the Hospital	Yes 1 Head of Patient Experience 1 Patient Experience and Involvement Officer 1 Information Analyst 1 Equality and Diversity Lead 1 Patient Relations Service Manager Several Complaints Resolution and Investigation Officers (plus complaints administrator and secretaries) Administrative and clerical support
Board-level responsibility for patient experience	Director of Nursing	Director of Nursing	Director of Nursing	Director of Nursing	Nursing & Patient Services Director
Report to Hospital Board	Yes - Board meeting opens with patient story and is a Patient Experience standing item on (a) formal complaints (b) local patient survey and FFT results	Yes - as part of Quality Report (Patient Experience section written by Head of PALS); Chief Nurse presents FFT results (without open comments) & a patient story/film/NHS Choices extract or audio clip	Yes – Board meeting opens with patient story. Patient experience part of 'Integrated Performance Report' (which is informed by 'Safety & Quality Committee' report – see below)	Yes – monthly Integrated Performance Dashboard has 3 dashboards dedicated to Patient Experience. In addition, 6 monthly Patient Experience Report goes directly to Board.	Yes – Head of Patient Experience presents a quarterly Patient Experience Report to the Board.
Links between patient experience & QI	Patient & Staff Experience Committee reports to the Quality Assurance & Learning Committee (consider FFT, local survey, complaints)	Head of PALS reports to Improvement Programme Manager, presents FFT data and comments & complaints data to Patient Quality Committee, and writes Patient Experience section of	Patient experience and QI come together at Quality Governance & Learning Group (where reports each team produce discussed to avoid misinterpretations and then collated into a single 'Safety &	Through the Quality & Patient Experience Committee, ward accreditation process, and Patient, Family and Carer Experience Steering Group Also at divisional and clinical governance.	Patient Experience Steering Group (reports to Clinical Governance & Quality Committee) includes Head of Patient Experience and Director of Quality & Effectiveness. Patient Safety

		Quality Report	Quality Committee' report)		and Quality Review Panels chaired by the Medical Director
--	--	----------------	----------------------------	--	---