Supplementary Material 6: Focused descriptive account of exemplar text comments for comparison with text mining

Incorrect receipt, criticism or misunderstanding of purpose of feedback survey

Comments in this category were included even if they were under 10 words long, as whilst we were going to trouble of examining c.2500 comments manually, it seemed prudent to examine some comments which the text mining algorithms would (perhaps correctly) consider to constitute "noise." Twenty-seven references were contained within this category. The 24 from the General Hospital subset mostly referred to circumstances in which the recipient had either "never" attended the hospital or their appointment had been rearranged and they had not yet attended, as in:

> "… You sent this survey but not had the appointment yet."
>
> "I havent been to [the hospital].... ???
>
> "Ive not received an appointment yet. This text is the first Ive heard about any appointment"
>
> "My appointment was re-arranged so i haven't been yet"

A handful of people were critical of the survey itself, including the subject matter or questions posed, purpose, methods or else sceptical about the potential utility of the results. One noted that they had already provided extensive feedback in clinic but were now being asked for more. Such comments were sparse and all from the General Hospital set:

> "I carefully completed a 3 page questionnaire at the clinic. Why are you now pestering me with multiple unnecessary requests?"
>
> "Hospital is extremely good, service was excellent this service is terrible, you gave me 6 choices, communication was the closest, think about feedback system, just gathering garbage data"
>
> "Let me think. Would I recommend someone in fear of potentially life-threatening illness go to A&E? Yes. Would I recommend A&E do market research like a business? No. Grow a sense of common decency ffs! END PRIVATISATION OF THE NHS NOW!"

The fact that the invitation to participate in the General Hospital survey itself appeared as a patient comment, in a dataset which had already been substantially "cleaned," says something about the potentially "noisy" nature of these data:

> "This is a message from [Hospital X]: We would like you to think about your experience in the Outpatients Department during this visit. How likely are you to recommend our Outpatients Department to friends and family if they needed similar care or treatment? 1 Extremely likely, 2 Likely, 3 Neither likely nor unlikely, 4 Unlikely, 5 Extremely unlikely, 6 Dont know. Please reply today, your feedback is anonymous & important to us. Replies to this text are FREE of charge. Please text STOP if you do not want to receive further texts from the trust. Thank You."

In a similar vein, one recipient appeared to assume that feedback was required around mobile phone provider. Not an unreasonable assumption given the format of the survey perhaps:

> "Good Internet reception and calls..but there are cheaper networks."

The three related comments from the mental health set appeared to represent a lack of clarity around what that particular survey was asking for, or else highlighted a potential conflict between giving service improvement feedback in the context of possible legal or complaints procedures:

> "Oh drat! I can't think of anything! Give me time …. I'll email if I do."
>
> "How can I answer that when I can't even 'improve' my own life?"
>
> "Please investigate the responses in this document with Greater Manchester Police and my Solicitor [identifiers removed]"

The latter comment does however point to a common tension or theme across the whole dataset related to the manner in which feedback was presented. Whilst the majority provided anonymous feedback, many went out of their way to name specific consultants, nurses, therapists or other care staff (including receptionists) sometimes with an explicit or implicit request that the feedback (which was usually positive in such contexts) be passed on to the named individuals and/or the whole team involved in care. The analysts do not know whether, as in the above example, issues related potentially (as they are not named) to safeguarding issues or the criminal law would be followed up. The General Hospital

invitation to give text feedback (see above) states that feedback is anonymous, so it is not clear how patients could or would be identified if follow-up on their feedback was indicated, as in cases of alleged medical error or professional malpractice for example.

Access, process and discharge

The clearest differences between the service feedback was seen in this node. Whilst similar proportions of references in both data sets addressed these issues, reference to the qualitative count data (table 4) showed that several issues appeared almost exclusively in the General Hospital data set, i.e. “speed and timeliness of access,” “waiting time at appointment,” “good accessibility” and “good process”. Having analysed all the data and by further reference to table 4, there appears conceptual coherence with “car parking” and “routing and signage,” which are also general hospital access, process and discharge concerns. Mental Health service comments around access were more likely to refer to waiting times to access services in the first place (rather than at the allotted appointment time in the service). These overall findings appear consistent with what we would expect and also with contemporaneous knowledge about increasing waiting times to access mental health services in the English NHS.

There were 117 General Hospital comment references attached to the “speed and timeliness of access” child node. On inspection, it was found that only 2 of these comments displayed negative sentiment, whilst the majority were praiseworthy. These comments appeared focused on staff efficiency and related process issues, e.g. good process decision-making by staff. Conceptually, the vast majority belong with “good process,” where some have already been coded accordingly. The one comment found from a Mental Health Service user in this child node was praiseworthy that they had received support so quickly, which appeared to run against the tide of the many more who were critical of waiting times to access services.

There were 115 references to waiting times at appointment, although in the 2 Mental Health comments it was not clear whether these related to waiting times prior to, or at,

services. The 113 General Hospital comments were split roughly half between positive (n=63) and negative (n=50) sentiment. On occasions, respondents said they hadn't minded waiting a long time in light of the excellent service or because staff were under pressure in busy services (seen also in unique child nodes on these issues and in the qualified comments).

In respect of process issues, whilst comments reflecting a "good process" came almost exclusively from the General Hospital set, a similar proportion of references from both data sets indicated a "process problem." In the case of Mental Health service comments, these again highlighted issues in trying to access services in the first place, as well as various other processes up to and including discharge and follow-up:

> "It is the other healthcare professionals that lack knowledge in: a) diagnosing the illness b) referring patients to you c) providing easy access to funds. It took 5 years for me to get the help I so badly needed. I feel that there are little chinks of light in my life since beginning of my treatment. ....."
>
> "Once when I called in advance to cancel an appointment, the message was not passed on and my counsellor sat and waited for me. The next week when I showed up she did not expect me, it was lucky that the appointment space was still open."
>
> "I wish I could have regular appointments and care with the staff …… but I'm left largely unsupported to deal with my issues on my own using the information / advice given ."
>
> "I am very annoyed. I have been discharged back to my doctor within the help. I told my Psychiatrist to send the letter in the post because I will forget. I think she put it on a paper what I misplaced and now I've been discharged, so you need to send letters out with appointment."

Comments about process problems in the General Hospital set were varied and related to all kinds of issues including service operating hours, staff competence in detecting

symptoms and making appropriate referrals, medication fulfilment, communication issues around staff engagement or awareness of a patient's history or current medication list. The content of some of these references was quite "rich" and they derived from comparatively lengthy comments that were often useful in describing and sometimes identifying what had gone wrong, making them useful for service improvement purposes. As with some of the other 'core' child nodes, these comments also underline the interplay of different issues, factors, or –as considered herein-"nodes":

> "I felt like the GP did not listen to me, prescribed me medication I cant take because it makes me ill and refused to believe it made me ill then told me to go to my doctors to be referred for an X-ray even after I told her I did not have a GP in the [identifier removed] area."

> "I had a long wait despite an urgent situation and the consultant I was referred to refused to even investigate the problem for which I was referred. Because the long term situation has not been resolved or treated appropriately I now face not being able to breastfeed my baby, due in 3 weeks time. I am outraged and very upset by this. | Please note the dermatologist you referred me refused to re-swab to check an ecoli infection had cleared. Given that my baby is due in 3 weeks I persisted on the reswab as symptoms had not settled. One was eventually taken but I have just been informed the labs did not receive it. I may still be infected and now have to wait another week without treatment until 2 weeks before my baby is due. This calls for a formal complaint."

> "There was not enough staff on the ward and I was put on a ward that staff (not there fault) didnt know my health issues waited all day for medication that was supposedly sorted to find out the next day it hadnt even been ordered lack of communication ."

> "The care was exceptional and thorough however there was confusion over the way the biopsys are booked. I was told by the consultant I could get a date within two weeks at the desk and the lady at the desk said Id be wrote to and there was a very long waiting list. My hair loss reversal depends on quick treatment so the end of my experience has left me very worried"

“All the staff are lovely. I do feel theres either a communication breakdown or you are understaffed or underfunded”

“The least helpful was a slow discharge; my notes werent to hand and then the booklets were upstairs. It was unnecess arily slow as I stood ready to go. I was disappointed not to see a physiotherapist. The nurse was vague about the answers to some questions. I noticed the physio sheet re a clinic strongly advised attendance before surgery which I had no idea | I hoped the booklet would show some exercises for the early post op days. I am relying on the internet for thst advice.”

“Im completely bed bound, which is known on my notes, but every time I have to visit out-patients for an appointment Made weeks, months ago. They always struggle to find a room to put me in, cos Im on a stretcher, even when Ive spoken on the phone beforehand, to tell them Im coming on a stretcher”

“Overall my treatment and care was first class. Unfortunately my experience was marred right at the end by having to wait for over six hours for my meds to come up from pharmacy. This was despite numerous and repeated calls from ward staff.”

“The paramedics were excellent The staff took far to long to deal with me and When they did attend to me they worked at a snail Pace I was not checked over throughly I had to point out my head needed stitched and arm needed seen to as it still had glass in from the RTA it also turned out my arm needed stitched I was left with a student to clean my arm with no one to supervise the doctor gave me no after care advice what so ever I dont even know when I can wash my hair after having stitches put in andMy head being full of blood I was discharged in excruciating pain in my chest head and bac”

“I had to wait 1 hour for my appointment and once I was called through I was sat in a room on my own for half an hour, once I had been see by a doctor I was left in the room with a bed that had been pulled in front of me and 2 chairs also in the way of the door, which had been closed when the doctor left the room, as I was on crutches I found it very difficult to get out of the room and was not happy

that I did not get offered any help to at least get out of the room after my appointment”

“Didnt know what i had come. For could. Not read. The. Form. Or find. My. Mri. Scan”

“Discharge procedure needs work though. Too rushed and it felt like they could not get you out of the door fast enough. | Got shifted off to the discharge lounge within 1/2 an hour of being told i was being dischargef, a place none of my visitors had been to and they then had to find it to pick me up. No sick note given as i couldnt speak to the doctor about it, as i had been moved off the ward. Will have to visit GP now instead. | ** some text is missing ** d to find it to pick me up. No sick note given as i couldnt speak to the doctor about it, as i had been moved off the ward. Will have to visit GP now instead.”

“Because I was kicked out of my bed 20 mins after having a LP [? Lumbar Punch] and sat in a day room told Id have results in 1 hour, left me there for 6 1/2 hours and nobody checked on me and I was admitted for suspected bleed on the brain, after 6 1/2 hours still no update and refused to give me a bed even though I counted a minimum of 12 empty beds on [the ward] so I discharged myself to go home to lie down as I was in a lot of painNot acceptable!!! I have started a complaint through PALS and will not return to [the hospital] in the event of an emergency, the hospital is lucky I did not have a hemorrhage in that room and something se”

“Really bad service, waited around to have a surgical dressing changed to be sent home and told nobody was trained to do I”

Differences in perceptions of staff and patient centredness

Staff were seemingly referred to in more positive terms in the general hospital set than in the mental health service set, with some codes or descriptors seen exclusively in general hospital derived comments: “above and beyond, attentive, calm, gorgeous, honest and welcoming,” although numbers involved were small. “Above and beyond” was an

interesting child node as it was made up of mainly of colloquial descriptors, as seen in the following highlighted comments:

> "I had sinus surgery and had to stay over night. I was made very comfortable and even though it was unpleasant (especially when them tampons were pulled out) the doctor and nurses who seen to me were absolutely lovely and put me at ease. [removed to preserve anonymity]. **Everyone can see the pressure youre all under and youre still doing a top job, all of you. Hats off** x
>
> "I haue beem a patient for mamy years amd have always been well looked after amd treated with with kindess amd **thd the nurses have always gone that xtra mile**
>
> "I arrived at the hospital to find out due to a mix up my appointment had been cancelled, after explaining I had travelled for 90 mins by bus I was passed on to a member of staff, unfortunately I did not get her name, however **she went above and beyond what you would expect and managed to get the consultant to see me**.I cannot praise her highly enough and would be grateful if you could pass on my thanks.
>
> "Staff were very decent people, **15 hour […] shifts the worlds gone mad, i take my hat off to them all and intend to bring some chocs in as a thankyou**.
>
> "… Polite and friendly staff. **They all went out if there way** to reassure me and explain what would happen

As well as the colloquial English, another feature of these comments (as seen in many others) is the frequent spelling, keypad or "predictive text" mistakes characteristic of text messages; although not all data were collected by text message.

A related colloquial expression, "nothing was too trouble," was seen in the "Attentiveness" child node, the contents of which appeared to underline this is a feature of patient-centred care (see also below):

> “Like ti thank the specialist very much for his information and compassion **nothing was too much trouble,** he's hit the nail on the head thank him very much for his attention and compassion”

> “Hit the nail on the head” here appears as possible reference to satisfaction with a diagnosis or a recommended treatment plan, but without further contextual information it is difficult to discern precisely what this refers to. Upon scrutiny, “calm” appeared to coincide with a “patient” or “kind” staff posture which probably points to the utility of merging “calm” with “patient.” In a similar manner, the code “honest” appeared as a component of good clinical communication. The following comments pointed to “welcoming” as being a unique feature of staff appearances, although these examples also point to its role as a component of patient centred care:

> “Whole experience was superb staff welcoming, efficient and felt safe i was well reassured they were excellent

> “The care I received was 100%. Everyone was welcoming and reassuring. I didnt feel worried and was made to feel at ease. The same goes for the surgery I underwent by Professor [C]. Excellent.

> “The staff are amazing at [general] hospital treated me with respect and dignity and made me feel welcome amazing staff

In one instance, “welcoming” appeared to refer to the state of the building and facilities rather than to staff behaviour:

> “From the second you walk in, you can see how clean and welcoming it is. I didnt have to wait to see the consultant for more than 10 minutes. The consultant and nurse were fantastic. Made me feel at ease and answered all my questions. 10 out of 10. Really impressed

Given the differences seen in codes associated with patient centredness, it was felt fruitful to compare the comments seen in the main “patient centred” node between settings; as count data (table 4) appeared to suggest that views on patient centredness and the

subjective feeling of having had a positive experience appeared similar; if only in terms of proportions. “Good clinical team” and “kind” were also examined as part of perceptions of patient-centredness.

“Kind” appeared to the analysts as a vague concept in relation to healthcare and partly for these reasons the similarly vague “nice” was also put into this child node, which ended up a fairly large one, consisting of 93 references spread across the 4 data sets (2 x 1 of each setting for each analyst). Scrutiny of comments in both settings suggested that this node did not add any meaning above and beyond other issues which had already been coded, which were various. These words were usually used for emphasis but applied in various different contexts (e.g. help giving, level of care, communication, safety and reassurance, information giving or competence and efficiency, etc.). Together, they appeared as elements of overall care quality, but did not appear useful for the purposes of comparing data gathered in the two different settings.

In the mental health set, declaring having had a positive experience was mostly associated with perceptions of the effectiveness of therapy or other treatments. In comments gleaned from the general hospital, declarations of “a positive experience” appeared rather related to the experience of efficiency and good process although one also got the impression of patients who had been left somehow “better off” (as in reassurance) following their interaction with the service, as in the following comment:

> “… Didn't wait, went in on time, efficient consultant was very good, clear concise, i came away feeling better what i have to do he reassured me that if i had an operation it would be fine, it was a good experience (General Hospital set)

In other comments in the General Hospital set, “made to feel important” appeared as a component of having a positive experience:

> "Prof. [Z] and his very dedicated team of amazing staff. Nothing is too much trouble for them, the treatment I have received I can only liken to 5 star rating, I was made to feel so very special a" (General Hospital set)

Other indicative comments include:

> "I felt like I was the most important patient in the world" (extract, General Hospital set)
>
> "I was seen promptly, the staff were professional and reassuring, as pleasant an experience as one can expect from a hospital appointment" (General Hospital set)
>
> "I found the whole experience completely stress free. I was extremely impressed with the efficiency and friendliness of all staff that I encountered during my visit." (General Hospital set)
>
> "My waiting time was minimal given the number of members of the public to be seen and the subsequent triage and meeting with an Advanced Practitioner was a most pleasant experience... the service was professional but friendly and efficient without feeling rushed and most importantly I felt cared for... Well done!" (General Hospital set)
>
> "Nurse very good in triage, had a terrible rash, saw this young doctor he made me feel confident he was so understanding he was brilliant, medication has worked, he was really marvellous, enjoyed very minute of it, **loved** [hospital] **to bits**, staff and everything"

Note "love to bits" as used in the last comment above to indicate care quality; never mind reference to "gorgeous" clinical specialists (although this was only seen in two comments).

The code "Good clinical team" reflected issues of competence that were seen across the whole service, rather than an individual staff members (as more usually the case in "THE STAFF APPEARED: clinically competent"). The count data suggested similar feedback in both service settings, and the comments revealed little. "Good clinical team" appeared mainly as

a magnifier or indicator of other or collective aspects of perceived care quality or positive service experience. A small number of references in both datasets pointed towards the ways in which clinical teams worked together or were “close knit” (as in the reference below). Such matters are probably the unique contribution of this node:

> “More efficient, more regular. They check patients every 15 minutes which I think is a very goo diea. They are very helpful, always keep a cool head and always remain on the ball. They try to give everybody the same courtesy, good or bad, always assertive. I have nothing to say, but good, about all the staff on X Ward. Well laid out programmes. They are extremely top of it. I think they are a very close knit team. I couldn't disagree in any of the running and most of all they were extremely nice and good to me when I was akward. Thank you very much. Your ace.” (Mental Health service set)

“Patient centredness” is an example of a code where data has sometimes been interpreted by the analysts rather than principally reliant on looking out for a particular word or phrase (as in “car parking,” “clean,” “I felt looked after,” etc). That is “patient centred” was not usually the term used by survey respondents themselves, although it was found in 32 general and 6 mental health service comments; as opposed to the 84 (general) and 10 (mental health) references attached to the node “patient centred”.

In the Mental Health service set, examples of patient-centredness included involvement in decisions around treatment and being listened to (as also classified in other discrete nodes). One comment said that services need to involve patients more in decision making, although others were positive. In the General Health set, patient centredness was also ascribed to individual help received, e.g. in respect of activities considered as going “above and beyond” (as explored at the beginning of this section) or responsive to specialist patient needs, as seen in the following indicative comments:

> “… Very impressed with my visit, i was very breathless when i arrived, pleased with your system, offered to get assistance to return back to my car after the visit” (General Hospital set).

> “Absolutely excellent staff who completely understood the needs of my daughter who, amongst other complex needs, has autism. All the staff were wonderful!” (General Hospital set).
>
> “The staff are very helpful in directing to the appropriate location for my appointments and always offer me support (Im a wheelchair user), they make me feel like I am able to be independent but are always willing to help. When rebooking appointments they are always considerate of my needs along with those of my carer.” (General Hospital set).
>
> “The person I saw was very thoughtful to my disability when doing the test requested and very reassuring.” (General Hospital set).
>
> “Clean, calm environment. Main reason, the medical professionals I encountered were caring, explained everything well and reacted quickly and didnt keep me waiting. They were understanding that I had my newborn son with me and helped accommodate us” (General Hospital set).
>
> “Was seen very quickly was made to feel a person not a number” (General Hospital set).
>
> “Professor [Q] provided some of the best medical care I have ever had. An un-rushed, thorough and informative appointment that not only addressed my physical needs, but my emotional wellbeing too. The NHS need more medical professionals at this calibre.” (General Hospital set).

As in the Mental Health service set, there were isolated instances where the antithesis of patient centredness was apparently being described:

> “I was very happy with the surgeon but this is the second time coming in for surgery on day ward. It feels like back in the days of Florence Nightingale. I think its awful that your spouse cant stay with you. It feels like a surgery factory. Would not recommend to anyone!” (“General Hospital set).

Comments indicating a lack of patient centredness in addition to those already considered were seen more in the Mental Health set (6 vs. 1) although overall numbers were small:

“No involvement whatsoever, decisions were taken for me and I was let down by the discharging team.” (Mental Health set).

“ up to visits, return calls, call when promise to. Not go on about in a rush or haven't got much time, that is not the patients problem.” (Mental Health Set)

Specific Complaints

The count data suggested that Mental Health service users appeared more likely to articulate specific complaints. These were often around inadequate staff numbers, outdated or unsuitable facilities and a lack of activities (the latter presumably for inpatients, although no sub-analyses were undertaken, e.g. of specific clinical units or departments). All numbers involved were small, except for “not enough staff” and “unsuitable facilities” where there were also comments from the General Hospital set. Food was praised by some and derided by others. More people seemed dissatisfied in mental health settings, where there was seen to be less choice and variety available. However, all figures were small and the variance in views seemed to reveal little of analytical importance.

Staff posture: clinically competent, friendly, helpful and polite

In reading hundreds of comments verbatim, the overwhelming sense was of people who were satisfied and in some cases literature astonished at the excellence they had encountered in terms of care quality and staff attitudes and professionalism. There are heaps of literal praise directed at NHS staff here; especially so in the General Hospital set. Some people who experienced poor elements of the service were able to relate these to discernible pressures on staff, “busy” departments or even the perceived effects of government policies. Thus whilst these comments reflect what is known from other sources, e.g. about the particular pressures on A&E departments or Mental Health services, they are

a useful tonic (especially for staff) in the general media and social media doom and gloom around contemporary health service provision.

Other sections of these results have already indicated how seemingly different aspects of the services are being valued when comparing positive with negative comments in the two data sets. Whilst the fact that “some staff are better than others” was recognised in comments from both services, more were seen from Mental Health service users, underlining that the fit or “gel” between professional and client can be key in the therapeutic relationship. A sense that staff shortages are felt more acutely in Mental health services could be explained simplistically by the fact that people are the main resource.

In the General Hospital set, satisfaction, good outcomes or reports of a positive experience seemed rather associated with perceptions of clinical competence related to the processing of a medical case.

Communication from and with clinical staff

In the Mental Health service set, the 2 references contained in the node “good communication from staff” referred to being kept up-to-date about staffing changes and waiting times. In addition to being kept informed, the 116 comments in the General Hospital set were more usually concerned with how staff had explained medical matters. Staff who “took the time” to explain things, or who were able to offer “concise” explanations were highly valued. As would be expected, there was some overlap with other themes here – notably from the “the service made me feel” and “the staff appeared” nodes; with comments reporting people feeling “at ease” following explanation or else experiencing “comfort” or “happiness.” Staff who took time to explain things were viewed as “helpful” and also “kind” or “lovely.”

Negative perceptions of communication appeared more prevalent in the mental health set, although absolute numbers were fairly small. The main issues centred on a perception of not being listened to by staff. A specific communication issue emerged in both data sets around support for people with hearing difficulties.

The service made me feel

Perhaps commensurate with the more commonly used descriptors of General Hospital staff in comments (see section on "Staff Posture," above), these comments were more likely to contain reports of feeling "cared for," "comfortable," "well informed" or "put at ease." At the same time, service users in both sets reported feeling as if they had a positive experience and proportionately more Mental Health service comments primarily reflected being satisfied with the care received.

Negative comments in this node suggested differences which again underlined the inter-personal nature of some treatments for mental health problems ("discriminated against," "ignored") although the numbers of references here was small.