



to Social Science

Beyond the checkbox Understanding what patients say in online feedback

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The project



- ESRC Knowledge Exchange grant to examine written feedback posted online to the NHS (March 2013-September 2015)
- 12 Research Questions given to us via Patients and Information Directorate, NHS England
- A 9 month project with 1 full time researcher, Gavin Brookes

Outline



- 1) The UK National Health Service
- 2) The corpus
- 3) Analysis
 - 3a) Lexical markers linked to quantitative rankings 1-5
 - 3b) Evaluation of staff members
 - 3d) Sex/gender and evaluation
- 4) Conclusion

The NHS



- The National Health Service is the largest and the oldest single-payer (e.g. state) healthcare system in the world.
- Founded by the Labour government in 1948
- Funded by taxation and National Insurance payments
- Most services free to legal residents. Some (emergency treatment and treatment of infectious diseases) free for everyone, including visitors
- A 2016 survey by Ipsos MORI found that the NHS tops the list of "things that makes us most proud to be British" at 48%
- Criticisms have involved antibiotic-resistant infections, waiting lists, scandals (Alder Hey)
- Recently, the government has been accused of trying to "dismantle" the NHS (Independent 27 August 2015)

Studies on feedback



- Often based on small datasets (100s of comments) (Jung, Wensing and Grol, 1997; Lagu et al., 2010; Lopez et al., 2012)
- Or specific areas of healthcare provision (Vingerhoets, Wensing and Grol, 2001; Platanova, Kennedy and Shewchuk 2008)
- A lot of research focussed on data collected in the 1990s and early 2000s
- Much work based on analysing check-box data (e.g. Ipsos Mori)

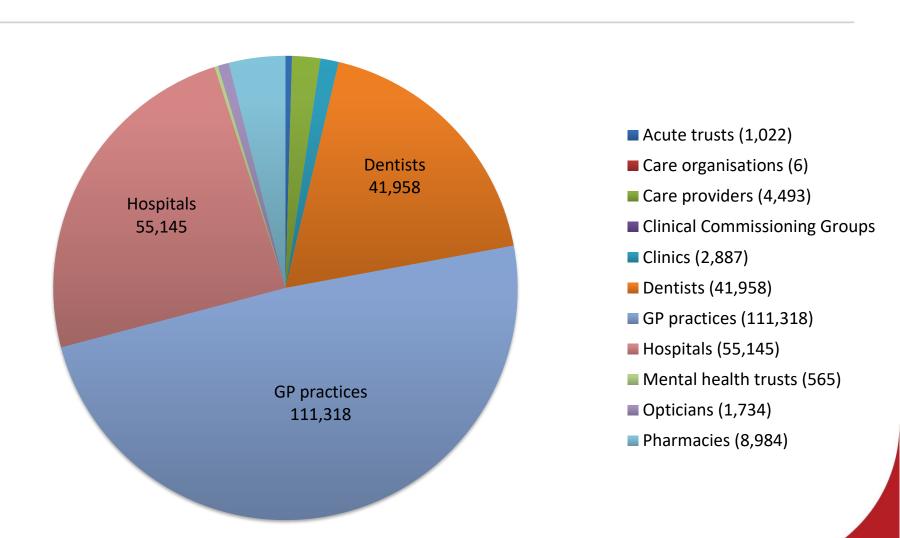




	Word count of patient	Word count of NHS	
	comments	responses	
GPs	14,093,437	5,596,738	
Hospitals	8,605,580	4,218,888	
Dentists	4,306,698	1,460,343	
Pharmacies	690,629	117,858	
Care providers	422,133	25,032	
Clinics	400,813	110,485	
Opticians	179,493	41,994	
Acute Trusts	159,385	63,933	
Mental Health Trusts	111,557	57,284	
Care Organisations	1164	0	
Clinical Commissioning	253	0	
Groups			
Total	28,971,142	11,692,555	



Number of comments per section



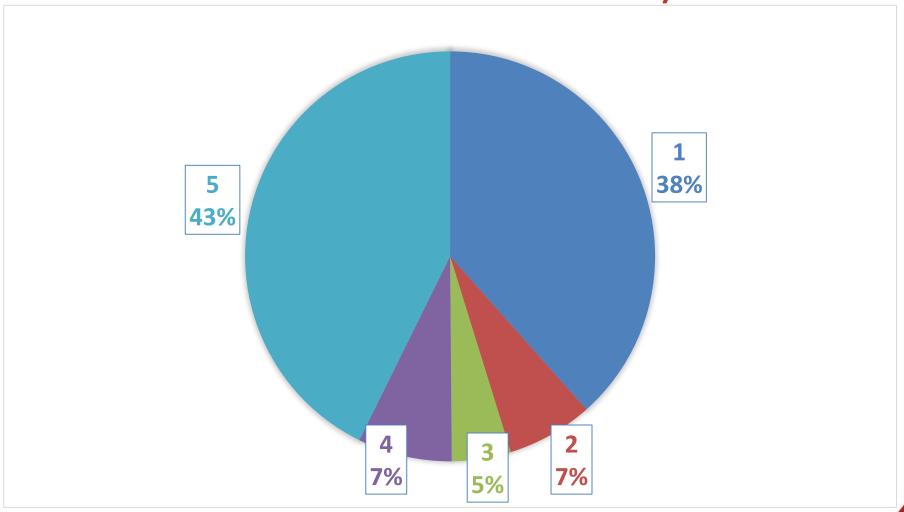
Some issues to consider



- The corpus consists of patient's perceptions, involving memories of a situation where they may have been in pain or distress
- We usually only have the patients' account of their experience: (TAKE forever 149)
- It is anonymous feedback and unlikely to have a negative consequence on the patient
- But not everyone can or wants to leave feedback



"On a scale of 1-5 would you recommend to friends and family?"



"On a scale of 1-5 would you recommend this surgery to friends and family?"

Rating	1	2	3	4	5
Total	6,134,193	1,094,411	724,682	860,393	4,349,330
words					
Total	39,954	7,066	4,838	7,733	44,398
texts					
Average	154	155	150	111	98
text					
length in					
words					

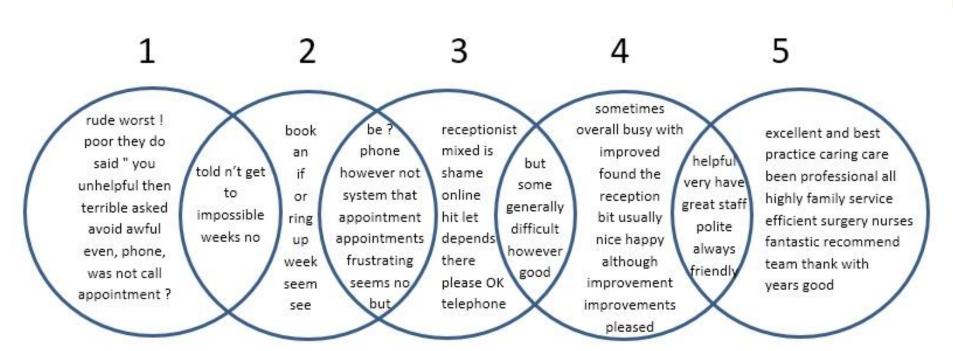


Adapting the keywords approach to compare 5 datasets

- Words which occur relatively more frequently in one dataset,
 when it is compared against another dataset
- Identify salient differences between two (or more) datasets which can be used as a focus for a more detailed analysis
- Can be used to compare e.g. differences between different datasets
- Five sets of comments each compared against the "remainder" e.g. set 1 compared against 2+3+4+5
- Results in 5 sets of keywords, with some overlaps

The "Olympic Rings"







Terrible feedback: keywords indicate narratives

- Appointment times are never kept to and have on a few times been waiting past an hour of my appointment time to be seen!
 (1)
- 38 days later was when I finally received my treatment appalling wait. Where is the compassion and the ethical values??? (1)
- I try to talk but I could not (I was shocked).. then they **said** "stop mumbling" I was before that screaming nurse about 6 minutes, then I **asked** them that no need to shout Just explain to me then I leave. (1)
- Was called in and once assessed by a new doctor, was told I needed my bloods done so was sent downstairs then told to go back upstairs to wait. What a faff on! (1)



Terrible feedback Question marks = Sarcastic humour

• The really hilarious moment, though, was when they put on blue rubber household (ie washing up) gloves in order to feel my legs. I mean, my legs are not going to give them some dread disease are they? And how could they feel anything through all that rubber? Temperature and texture would not be available. The whole consultation was a farce, and I might just as well have sat in front of a computer - myself. I am now thinking of applying to become a doctor! I would make just as good a job of it.

Terrible feedback: avoid



- Avoid like the plague unless you are able to predict your illness a week in advance and book ahead. (1)
- Avoid registering here if you can help it. (1)
- Avoid, avoid, avoid, do not register here! (1)



Bad feedback: seem and seems

- The surgery does not **seem** to be bothered about the level of patient satisfaction or take patients concerns seriously. (2)
- The doctor I saw didn't really seem too interested in what was wrong (2)
- The staff on reception just don't **seem** to care at all. (2)

Bad feedback: or



- 66 cases of rewording there is a difference between being assertive and impolite or rude) or listing 2 or more similar items (I or my husband), which can often have an emphatic function (I'm treated with little or no respect).
- 10 cases of listing 2 problems: I myself left this practice because of their inability to care **or** make appointments for their patients (2)
- 11 cases of being given 2 bad alternatives: The problem with this system is that you have to go in person just to put your name on a list and be given an approximate appointment time later that day, then come back again a few hours later, or you can opt to stay that time in the packed waiting room instead and hope you do n't catch anything

Bad feedback: if



- Collocate could: I asked if I could see another doctor and was told "we prefer you to see your own doctor". (2)
- Collocate can: The receptionist can be very rude at times. They become the judge of how ill you are and if you can see a doctor.
 (2)
- Collocate would
 It would be great if patients were given a choice of provider in teh surgery when they visit to speed up the transition from primary to secondary care. (2)



Middling feedback: but, however, mixed, depends, generally, some, shame

- all I want to do is see one of the wonderful doctors **but** the appointment booking system doesn't allow it. (3)
- The doctor has always treated me with respect, given me adequate consultation time and helped me through some difficult times. However; the surgery is old-fashioned and unwelcoming and could well do with a drastic refurbishment (3)
- Bit of a mixed bag (3)
- Generally good but depends very much on your doctor
- The doctors are generally very nice, although sometimes dont appear to be listening when you speak and trying to book an appointment is unbelievably difficult
- Good doctors, some very rude admin staff! (3)
- Its no wonder the reception staff never seem happy. Such a **shame** that these little or perhaps not so little things let this surgery down so much. (3)

Middling feedback is long



Availability of Appointments The Dr's at this surgery are caring, kind and exceptionally good; however getting to see one of them is more tricky. The reception staff are very unhelpful and although you are told when you try to book an appointment a day in advance that you can not pre-book appointments, unless requested by the Dr, amazingly all the emergency appointments that supposedly can not be booked until 'on the day 'are always' taken even if you call on the dot of 8:00am and the answering service has just been switched off. I am registered at the Branch surgery in Fazeley but often have to take appointments at the main surgery in Tamworth, which is difficult as parking is always an issue. The patients carpark is alway full and therefore you end up paying £2.40 for parking in one of the pay & displays; that's even if you can get a space in one of those. Public transport is not an option as I live in a village and there are no buses. It is a pity that these wonderful doctors should be tarnished by such support (3)





Context of please	Example	Number of cases
Request for	Please review your policies and systems so that only	79
improvement	patients who need to be at the surgery have to attend	
Quote from staff	I called to enquire about the date and time of an	5
	appointment and was told "You know, please write it	
	down in future".	
Quote from patient in	Can I have an appointment after work please?	6
reported conversation		
Staff didn't say please	The reception staff are rude, and instead of saying next	4
	please we get a rude yes.	
Advice to other readers	If you wish to experience this as i did please place your	3
	phone to your ear and set your child to screaming abdab	
	mode until further notice.	
Others	Maybe your sign should read please do not use unless you	3
	are disabled!	



Good feedback: sometimes, although, usually, overall

- Queue for next free GP or nurse sometimes a bit squashed but patient info on TV is good while you wait. (4)
- Staff are friendly although a little bureaucratic sometimes. (4)
- I am **usually** always able to get through on the phone but understand that the reception staff are extremely busy so If I cannot get through straight away I will leave it a little while and try again. (4)
- Overall the surgery is run very effectively and although some appointments can be delayed the overall expectancies are met in the main. (4)



Good feedback: improved

- Much improved over the past 12 months. (4)
- the <u>majority</u> of the doctors are pleasant and understanding but <u>occasionally</u> I feel the 'bedside manner' could be **improved**. (4)

Good feedback: nice



Context of nice	Example	Number
		of cases
Straightforward praise	It was nice of the receptionist to come out and	75
	give me a drink of water when I was having a	
	coughing fit in the waiting area.	
Nice but criticism	The receptionists are nice but sometimes	13
	ignore whoever needs assistance.	
Recommendation	They have now moved to new premises on the	10
	Tonbridge Road (Jul 2013): and it woudl have	
	been nice to have been informed (by letter)	
	when this had happened.	
Indication that someone is	be nice to people and they are generally nice	2
not nice	back they should try it .	

Excellent feedback: and



- Medical and all other staff are kind, efficient and very helpful.
- The waiting room is <u>uncluttered</u> and <u>well-decorated</u> with a play area for infants, lots of reading materials information on additional services such as alcohol and sexual health . (5)
- Booking an appointment with the <u>welcoming</u> and <u>happy</u> receptionists was completely hassle free and the treatment and care received from the Nurse Practitioner was nothing less than outstanding. (5)

Excellent feedback: surgery, practice, team, family, years, always, all

- I always get very good service at the **Surgery**. (5)
- I think this **practice** is absosultely fantastic. (5)
- Thank you to entire **team** for the great work. (5)
- I have been with this practise a long time, and the staff have always served my whole **family** well. (5)

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- I have been served by this practice for over 15 **years** and have received the highest standard of care in all that time. (5)
- All the reception staff are polite and helpful; it's always easy to get through on the phone and book an appointment (5)



Excellent feedback: thank and recommend

- Thank you I recently lost my mother. She suffered from cancer. I wish to thank the Doctors and staff for all the support my mother and family received throughout her illness. Anytime we called we were given A. star service. My mother was very fond of the GP and the Nurse who always went out of their way to help.
- Would Defintely recommend them as GP to anyone. (5)



Functions of leaving feedback

- Recommending (or not) to other patients
- Expressing emotions, especially gratitude, disappointment, frustration or anger
- Constructive criticism, making recommendations for changes to be made
- Sarcastic humour feedback as entertainment

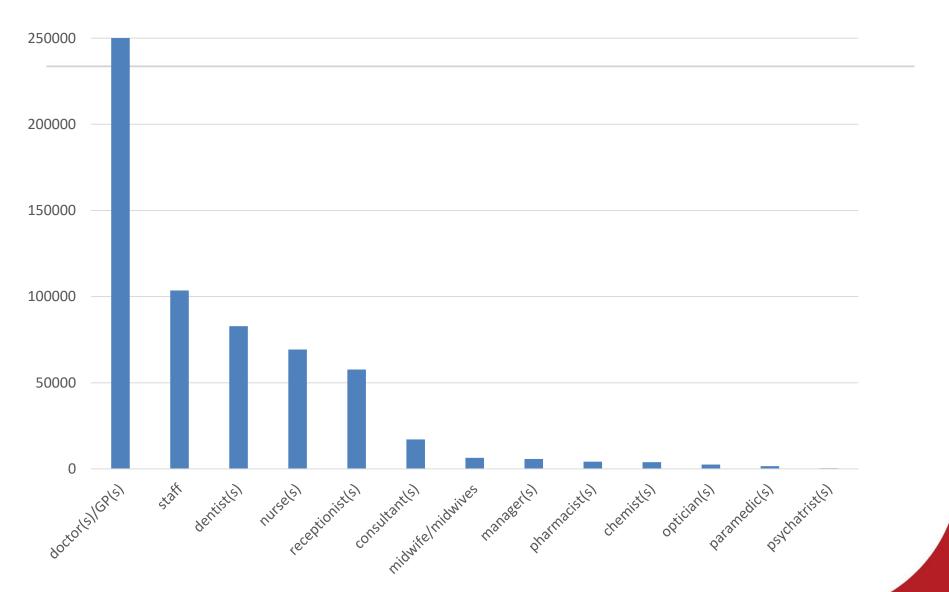
How to get a 1 (or a 5)



- 1 involves a single poor experience
- 3 involves a mixture of good and bad elements (as opposed to everything being mediocre)
- 5 involves consistently excellent care over a long period of time,
 and for multiple family members or friends
- 1 is not the opposite of a 5 (this is discrete and ordinal)



Mentions of different types of staff



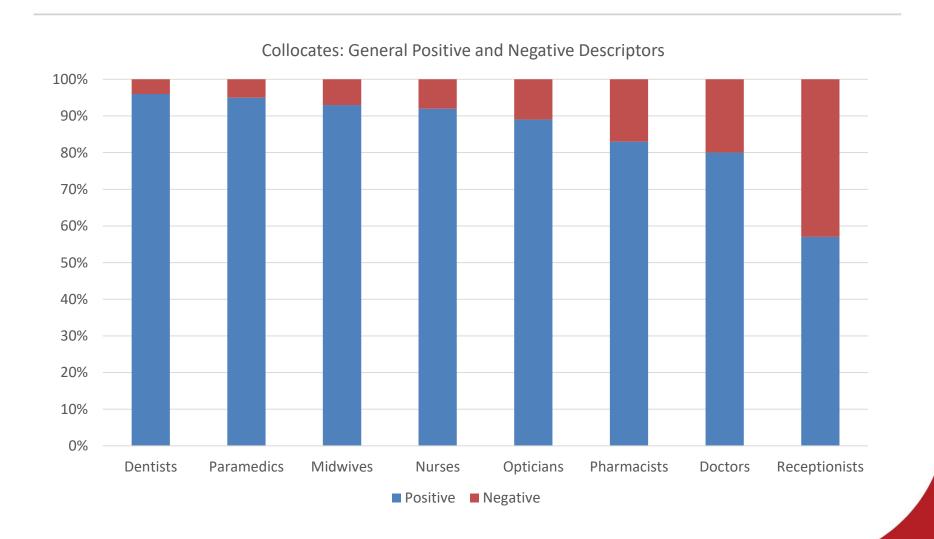




Positive		Negative	
good	59,237	bad	16,945
excellent	49,090	poor	15,274
great	34,298	worst	7,627
best	25,556	worse	7,289
fantastic	15,186	terrible	6,799
brilliant	11,546	awful	6,106
wonderful	10,371	appalling	4,410
amazing	9,749	disgusting	3,246
outstanding	5,019	ridiculous	3,206
exceptional	3,387	useless	2,461



Proportion of positive to negative evaluation





Some negatively evaluated receptionists

- The last and final time i tried to make an appointment at this Health Centre, the receptionist laughed in my face
- Receptionist interrupted talked over me on the phone, had to ask if I could finish my sentence three times.
- Upon approaching the desk I had to wait whilst the receptionist finished telling their colleague about their weekend, then when I asked my question I was given a response of "well it 's not exactly hard to work out".
- I was very surprised and disappointed when the receptionist refused to give me an appointment or to put me through to the doctor to discuss the situation.
- My daughter is now too embarrassed to go back when she was asked personal questions about the nature of her ailment by the receptionist.



Why do receptionists do so badly?

- Encountered by largest number of people?
- Gatekeeping role has capacity to annoy the "face" of systems they didn't design
- Questions mistaken as nosiness
- Is social class a factor? E.g. viewed as relatively inexpert so afforded less respect
- Is gender a factor? (94% of British receptionists are female)

Gender/sex differences



- 100 samples of self-identifying male and female feedback taken at random e.g. BE followed by (man/woman) up to 5 words away. + 17 cases of (transgender* | transsexual* | trans)
- 34/100 women gave positive feedback, 65/100 men did
- 10/15 transgender people gave positive feedback
- Men complained more about having to wait (21% vs 15%) and receptionists conducting triage (4% vs 2%)
- Women complained (slightly) more about being roughly treated (3% vs 1%) and the state of the premises (4% vs 2%)
- Transgender people complained about staff ignorance or unwillingness to engage with transgender issues

Men and pain



- Surely a receptionist knows that when most men come in to see a doctor its because they are extremely worried about something.
- I was seen x- rayed, treated really well, and then told off for not explaining my pain and told to stop biting my lip, and help them understand my pain, I explained I was a man, to which I was told I had damaged my ligaments and shown my x rays
- Now I am a big 6ft man who has under gone a lot of dental work and have never felt pain like it.
- I am a grown man but a baby about the dentist because I have very sensitive teeth
- The dentists are excellent and have always treated me with great care and consideration (being a man I can't bear pain.)

Women and intimidation



 I was a lone woman feeling very unwell and there were some very intimidating people in

 I am female, unable to walk and I felt not safe being driven for 40 minutes in the night by private taxi from Hailsham to Eastbourne.



Negative gender stereotyping

- One doctor was convinced I was a crack cocaine addcit without examining me just because they thought all the young men in the area are involved in drugs and crime.
- Men made to feel very unwelcome, practically felt like a sex offender.
- I drove up to the barrier to obtain my ticket but manoeuvred in awkwardly so that I had great difficulty reaching out to press and collect my ticket. Two car parking attendants stood at the front and rear of my car (there seemed to be a problem with the exit barrier?). The one facing me rolled his eyes and shook his head, clearly making a statement that I was a woman whilst I struggled to obtain the ticket, making no effort to assist me.

	Female Female	Male
People and groups	woman, husband, baby, female, midwife, women, lady, drs	man, male, men, wife, dentist
Pronouns	me, they, her, my, I	you
Grammatical words	and, around, after, on	of, the, non, this
Places	ward, room, hospital,	practice, NHS, surgeries
Auxiliary verbs	was, didn't, couldn't, did, am	have, been
Communication	notes, said	write, advice
Verbs	crying, booked, came	given, seems, allowed
Abstract concepts	life, experience, appt	referral, problem, appointment, money, doubt, consultation, results, visits
Adjectives	lovely, grateful, elderly, broken, nice, wonderful, amazing, impressed	good, poor, difficult, following, old, working, helpful
Time and quantification	never, first	times, always, years, year, minutes, recent, many, three, five, number
Adverbs		surely
The body	breast	
Health conditions	pregnant, pregnancy, birth, labour, midwives	bipolar, condition, dental, pains



Female first and third person pronouns

Since there was no available appointments for me, I had to take
a phone call consultation which I didn't mind. They told me to
bring in a urine sample and they would leave the antibiotics
with the receptionist. On arrival I was told that urine samples
had already been taken and the doctor had not left any notes
on what antibiotics they should give me



Male second person pronouns

- The doctors lack care and compassion. They fail to greet **you** with any courtesy, preferring to stare at their computers (while at the same time seemingly failing to absorb any of your medical history)..
- If you call when the switchboard opens more often than not the line is engaged. When you finally get through you are kept on hold for ages. Finally the receptionist (who is pleasant and approachable) answers and informs you that all of the appointments for the day are booked and that you will have to call tomorrow, and the cycle repeats.





 I must say that the nurses there are lovely and kind, and my doctor is lovely but hard to get an appointment with.

 The receptionists are so nice and one especially is just wonderful

Male quantities



• They always take between 20 to 40 minutes to speak with someone. Compare [Anonymised] to my previous surgeries this is at least 5 times faster. You should always remember a surgery has thousands of people registered and only a couple of administrators looking after it. If 10 people call at the same time you will have to wait for the 2 people working to get through them, which will take about 5 minutes a call, so 25 minutes if you were number 10!

Conclusions



- A lot of focus on social skills. Does that mean patients are happy with the medical treatment or they simply aren't equipped to comment on it?
- Feedback is related to expectation to an extent, and filtered through patient and staff identities.
- The practice of giving online feedback contributes towards a "market" discourse of the NHS. But the NHS is not a market. It does not set its budgets.

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