60 years of the NHS

Ordinary people tell the story

“For me, the NHS is a miracle in itself.”

Linda Lamont and Fran McCabe, February 2010
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Foreword

Linda Lamont jointly commissioned the following NHS Mass Observation directives: in 1997, with Professor Dorothy Sheridan, ‘You and the NHS’; and in 2008, with Fran McCabe, ‘How have you been treated by the NHS in the last decade?’ Linda has spent 25 years working on patient action and research. Originally an historian and teacher, she joined a local community health council, then became Director of the Patients Association for more than eight years. Subsequently she has been on the board of an NHS trust where she dealt particularly with complaints. More recently she has worked on Mass Observation health materials while an Honorary Fellow in Contemporary History at the University of Sussex, with support from the Wellcome Trust. Linda says:

The work I have done over these years from a patient’s perspective has convinced me that the majority strongly support an NHS free at the point of use. They see it as an irreplaceable institution. What is now needed is a patients’ history of the NHS as evidence of the bedrock upon which it is based. There is no substitute for people’s own words when writing about their experiences and opinions. The MO material we have studied for this report is an important part of the patient’s story.

Fran McCabe worked for over 40 years in health and social care. Originally a nurse and health visitor, she moved to social care and headed up social services for over a decade. She was a senior civil servant in the Department of Health. After a stint in the Social Services Inspectorate, she ran a programme on innovative ways of providing services for older people in a national team. She has an M.Sc in Geriatric Medicine, and an MA in Life History Research from the University of Sussex on a history of the NHS through general practice. Fran says:

I have only recently come upon the Mass Observation material. It is totally absorbing. The vivid stories going back to the beginnings of the NHS and before, give us a perspective we should not forget: that despite its problems, without the NHS, many people, especially those devoid of means, would not be alive today. People who have written to the MO Project are reflective and have foresight about the strengths and shortcomings of the NHS. They are aware of its complexity and discuss contentious issues around ethics and funding, sometimes suggesting practical solutions. Even when they have had problems using the NHS, they still hold its values to their hearts. I believe their thoughtful testimonies have a rightful place in the spectrum of research about patients’ experiences of the NHS.

Visit our website where you can download this report.
www.nhsnarrativesmassobservationlamontandmccabe.co.uk

Linda Lamont and Fran McCabe, February 2010

The Mass Observation Archive specialises in material about everyday life in Britain. It contains papers generated by the original Mass Observation social research project (1937-early 1950’s) and newer material collected continuously since 1981. The Archive is in the care of the University of Sussex and is housed in the Library in Special Collections. The collection is now known as the Mass Observation Project. More information: http://www.massobs.uk; or email moa@sussex.ac.uk
Acknowledgements

We would like to thank the staff at the Mass Observation Project, especially Jessica Scantlebury, for assisting us in working through the complexities of the Mass Observation Archive. Professor Dorothy Sheridan, Tara Lamont, Patricia Murphy and Dr. Duncan Stewart also advised us on the narrative, but we take responsibility for the final work. The Wellcome Trust supported the research in 1997 and the Care Services Improvement Partnership (an arms-length service improvement organisation, wholly funded by the Department of Health) funded the commissioning of the 2008 directive.
60 years of the NHS
Ordinary people tell the story

Introduction
‘For me, the NHS is a miracle in itself.’

The future of the NHS will be at the top of the political agenda in the coming months and years. Our aim is to ensure that the patient’s perspective remains at the forefront of the debate, by presenting the story of the NHS through the experiences and views of people who have had contact with its services. Our study is not an analysis of social policy or the politics of the NHS, but it reflects what those who use and pay for the NHS think about it. The accounts we have used are from patients and carers, who often feel that their personal stories are not recognised by those who run the NHS. For people who work in the health services, the study will provide an illuminating commentary alongside the many satisfaction surveys and statistical reports which are their required reading.

The source of our research material is the Mass Observation Project (MOP). Since it began in 1937, the MOP has sent out directives or questionnaires to its standing panel of writers, asking them about many aspects of their lives, including their health. We have examined responses to three directives specifically about the NHS. They relate to three key dates in its history: 1949, the year after it began; 1997, just before its 50th anniversary; and 2008, when it was 60 years old. (Details of the directives are in the appendix.)

We have read and analysed hundreds of the responses to these directives. They are an unique resource. The writers are volunteers of all ages who come from every part of the UK. What unites them is an interest in writing about their health experiences both good and bad, and voicing an opinion, often strongly held, about current controversial topics. They are not a statistical sample but within their ranks are to be found patients, carers, people who work or have worked in the health service and members of the public who care about the NHS as an important institution.

MO correspondents often think of themselves as ordinary but the immediacy and quality of the writing makes their contributions special. Many accounts are touching, some are humorous. The length ranges from a single scribbled sheet to a 15 thousand word essay; they may include press cuttings or drawings to make a point; each one is valuable in a different way. In one sense there is no such thing as a typical response, since each writer is an individual with a real life experience, but they often touch on common themes as the following chapters will show. Topics related to general practice, hospital and maternity care, dentistry, long term illness and the care of older people frequently appear, so we have focused on these but that does mean we have been unable to do justice to other important areas correspondents referred to, such as pharmacists, physiotherapists, alternative therapies or care abroad.

Our challenge has been to select short extracts of people’s actual words which are illustrative of the range of experiences and the weight of views in this rich material, especially when there are many responses which are worth quoting in full. We hope to publish an anthology at a later date.
Who are the MO correspondents?

In 1949, when there were 2000 people on the MO panel of writers, men outnumbered the women by three to two. On average, the men were in their early 30s, whereas the women, especially when single and working, were in their mid 40s. Addresses were not asked for, but occupations were usually given and were heavily weighted towards the professions, particularly civil servants, teachers and engineers, with only an occasional tradesperson (electricians, outfitters). Where women described their occupations, teachers and secretaries were outnumbered by housewives. The majority of contributions were well written suggesting a good educational background.

In 1997, there were 271 responses from a standing panel of 467 people. Of a sample studied in depth, three women replied to every two men and over a quarter were aged 60 or more. Of the rest, there were diminishing numbers over the decades, especially among people in their 20s and 30s. Although all parts of the British Isles were represented, with one or two responses from abroad, a third came from the London area and the southern counties of England.

The range of occupations, both in 1997 and 2008, was broader than in 1949, particularly for women. Professional and clerical jobs were most frequent, including about 14% who worked, or had worked in the NHS as doctors, nurses, administrators or secretaries. The range of occupations also included toolmakers and dinner ladies, counsellors and artists. Apart from mothers of young children, people only rarely described their occupation as carer even when it became clear from their response that this was their primary role. A number who were unemployed through ill health made insightful contributions.

Over a third of the respondents in 2008 had also answered the 1997 directive, providing an indication of their constant or changing opinions about contentious issues such as the ethics of medical research and euthanasia. Some people made comparisons of their health care experiences over a period of years. The response rate in 2008, at 235 out of a possible 480 on the standing panel, was just under half. By this time, more men and younger women had joined the panel so that the correspondents more closely resembled the general population.

While just over half of the respondents were over 60, the panel was generally younger; the youngest was 16 years. Once again, replies from the south east dominated (nearly a quarter), but responses came from all parts of the UK and we have tried to reflect this in our analysis. Thirteen nurses and nine other NHS workers replied, nearly 10% of the total, along with seventeen people from allied professions, such as social workers; thus we have gathered many different perspectives on the NHS.

There are many debates on the representativeness of the MO panel, which is explored in detail in D. Sheridan’s *Damned Anecdotes and Dangerous Confabulations* (see notes at end of report). In our view the variety and geographic spread of the panel from which the MO correspondents come, provides a valid reflection of public opinion. We hope the work will be read by health and social care professionals and policy makers, researchers, the media and interested members of the public. The report is in three sections. Part I covers correspondents’ experiences of the NHS over its 60 years’ history. Part II addresses views on contentious issues and the future of the NHS. Part III gives our summaries and messages from the research.
Contents

Part I
Mass Observers’ health experiences over 60 years of the NHS

1  Hospital care, cleanliness and communication
   ‘Basic hygiene is not something I associate with the NHS.’  1

2  General practice
   ‘I sincerely hope that I never need to see a doctor urgently.’  10

3  For better, for worse? Childbirth and maternity services
   ‘There were ten days’ confinement in my day; now you are sent packing as soon as you can stand.’  15

4  Living with long term conditions; patient support groups; mental health
   ‘I feel the NHS has let me down.’  22

5  The cyclical history of 60 years of dental services
   ‘There is no NHS dentist … I do miss my dazzling smile. I look like the wicked witch.’  28

6  Older people, including dementia
   ‘With the rising number of elderly citizens, the NHS is going to face its greatest ever challenge.’  32

Part II
Mass Observers’ opinions about contemporary ethical and political NHS debates

7  Ethical dilemmas in health care
   ‘We are fortunate so much research is going on.’  39

8  Health information, the internet and confidentiality
   ‘We still need humans.’  44

9  Priorities, preventative health and the public health debate
   ‘It seems everyone has rights but not all have responsibilities.’  48

10  The future NHS and how to pay for it
    ‘The NHS may not be the “envy of the world”, but it is still far better than any of the alternatives on offer.’  52

Part III
11  Authors’ summaries and messages  56

Appendix
Mass Observation directives on the NHS 1949, 1997 and 2008  62
Notes and references  66
Part I

Mass observers’ health experiences over 60 years of the NHS

1 Hospital care, cleanliness and communication

‘Basic hygiene is not something I associate with the NHS.’

Before 1948, sick people were faced with a failing hospital service. The voluntary system was inadequate even before WWII. The development of specialist skills, better surgical techniques and antibiotics, during and after the war, resulted in demonstrable improvements in medical care in the early NHS hospital services. Though shortages of money left buildings unfit for purpose, people were generally positive about free hospital care, as directive responses in 1949 show.

I reckon that if I had to pay the cost would be about £600, or more! This covers my weekly contributions for the rest of my life. I suppose those at work and paying would say it’s all right for you. The point is they never know what’s going to happen to them in the future, when if anything does happen, they will be very glad of the N.H.S. as I am. Glad and very grateful. [1040, single mechanical engineer, 27, recovering from tuberculosis]

It was “Hats off – all cards ready.” Under the new scheme … there was to me, a marked difference, four patients … not eight as before. There was quite a different atmosphere. [The consultant offers her an artificial eye.] Me: “Is this necessary at my age?” Doctor: “Certainly. And if you want anything done to your other eye just come back” … removing a sense of dread. One patient said: “If it is always going to be like this one need have no fear in coming here.” [019 a single lady of 79, on “home duties”, living in Dundee, describing an outpatients’ clinic]

1997, the NHS at 50

‘Money should be channelled into medical care … not bureaucratic side-kicks and wasted.’

In 1997, correspondents continued to compare favorably pre and post NHS services and older people were sanguine about shortfalls. Though some of their stories may have been nostalgic, they do give a consistent description of early health care and they are also important in shaping a collective memory of the early NHS.

I … remember pre-NHS hospital waiting rooms … the smell peculiar of the times … a mixture of ether, iodine and floor polish … the lights hung from long flexes and had porcelain shades shaped like a Chinese coolies headgear … and hovering over rows of hard wooden forms, is the hushed air of dejection and the vulnerability of those exposed to the military-style discipline. Bandages were used time and time again, and while awaiting treatment patients were expected

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1 Italics are used for direct quotes from MO material.
2 * * are used when correspondents directly quote;
3 ′ ′ are used for quotes within our narrative;
4 ... indicate that quotes have been edited;
5 [ ] indicate link phrases of explanation.
6 Mass Observation correspondents are recognised by alpha numeric codes which follow them through all their reposes. Most also provide other demographic details about themselves: gender, age, location and occupation. This information is provided in [ ] at the end of narratives.
7 Where capitals and underlining are used in quotations, they are the correspondents’ not the authors’.
to have these re-rolled in readiness. Only workers paying a weekly stamp were covered by insurance for medical care. Other members of the family could expect to pay a doctor’s bill. Hospital treatment for those unable to pay was not denied but I remember a system whereby a ‘recommend’ had to be obtained. [R1418 m 75 Derby, ret decorator]

When I think of the regime when I was in hospital in the 1950’s [with TB] … nurses had time to give Tender Loving Care. It was normal then, for visitors to bring in half a dozen eggs, fresh from their own hens or the staff would happily boil them for our breakfast. My mother would bring in a small home-made Shepherds Pie (my favourite food ) and at lunch time it would be reheated for me. Nowadays, according to Reports, Patients have to send out for Fish and Chips or a Chinese takeaway because the hospital food is inedible. [G1241 f 75 Frome, ret receptionist/typist at GPs]

As long as I worked for the NHS, there have been grumbles about waiting lists, queues at clinics. Doesn’t seem to have changed that much but I do think people look for complaint at times – perhaps the influence of TV programmes such as Peak Practice and Casualty. People are more aware of what to expect. [G224 m Bath ret higher clerical officer, NHS Medical Records]

Through my work, I visit or meet many people with experience of hospitalisation and they all make the same comment, “They were wonderful”. [H2161 f 85 Hereford, ret teacher, C of E Minister, working in mental health]

NHS facilities
‘Anyone would have thought it was a temporary facility in an emergency disaster zone in a Third World Country,’

Positive comments on hospitals were noticeably tempered with concerns about the persistence of dilapidated buildings, parking problems and long waits for treatments. Correspondents wanted something done about nursing shortages and the generally poor hospital morale. They were highly critical of the burgeoning bureaucracy and underinvestment in the NHS. Typically they believed that ‘money should be channelled into medical care’ [B1378], not ‘bureaucratic side-kicks and wasted’ [G1416], and that the ‘internal market should be stopped immediately’ [A2212]. Here are examples of their comments.

There was nowhere to park as disabled bays were occupied by able bodied people … The burns department was in a shabby prefabricated building where we had to wait for over an hour on a hard chair (because my appointment had been incorrectly booked in), and I was eventually treated in a corridor next to an open door onto a quadrangle of sun-baked mud where clouds of dust and large pieces of rubbish were blowing about … Anyone would have thought it was a temporary facility in an emergency disaster zone in a Third world Country, but actually it was a routine visit to a large hospital in a wealthy area in the south of England. [A2212 f 40 London, tutor/writer, visiting the OPD]

We have a-state-of-the-art-hospital. The best in Europe. So good it’s rusting at the seams. I have told my family they are not to send me there, but they will of course, they won’t let me rot in my own bed. A friend visiting there recently, was looking for a room to have a puff, and wandered into a corridor with space suits hanging outside … She discovered that there is a flesh-eating disease still lurking, although the publicity has moved on. [B1180 f 69 south coast, ret clerk]

[I would like] more nurses … increased pay to tempt them in … less paperwork for them. Let them use their knowledge … Open up closed wards in every hospital, no more travelling miles because there are no beds locally. [A1733 f 70 Birmingham, ret chocolate factory worker]
Wants] enough staff, adequate numbers of beds, suitable equipment, both sophisticated and conventional, upgrading of dowdy or inappropriate accommodation, good hygiene. [B89 f 77 Leighton Buzzard, ret audio-typist]

2008, the NHS at 60

‘Improvements in treatments, waiting lists and rights, but deterioration in cleanliness, friendliness and nutrition.’

It might be expected that there would be a marked difference in experiences by 2008. The NHS Plan had been introduced in 2000 specifically to address finances, staff shortages, and improve the speed of access and standards of care; and it was followed up by numerous policy initiatives. There were stories about reduced waits for treatment; of clean wards and perceptions that depictions in the media about poor hygiene had been exaggerated. There was praise and understanding of the demands on hospital staff, and examples of being ‘treated with dignity most of the time’ [J1890]. There were fewer complaints about dilapidated facilities, given the recent hospital building programmes.

However, the worries about cleanliness and dirt in the 1997 replies had increased in 2008. Stories of good care were marred by the fear of hospital-acquired disease causing suffering, even death. The blame for unhygienic conditions was attributed to the outsourcing of cleaning to private companies and the rapid turnover of patients, as well as the changed attitudes of nurses who were seen as no longer taking overall responsibility for basic patient care. For the first time there were numerous criticisms of the attitudes and standards of nurses and nursing, with calls to bring back ‘matron’, most people not realising that this role had been re-instituted. The following comments are just a few of the many on cleanliness in hospitals.

On cleanliness

‘A piece of paper stayed under the bed ... for over a week.’

According to the Daily Mail and several other newspapers the average British Hospital is a hellhole of infection, incompetence and imminent death roughly equivalent to Scutari before the arrival of the lady with the lamp. As you can tell from the sentiments expressed above it is a view of our national health service I do not share. [C3167 f 69 south coast, retired clerk]

[On the care of a sister, in her 30s with cancer, who referred to the staff as ‘brilliant’.] The [oncology] ward was filthy. The bathroom had to be cleaned by someone (family) before it could be used ... Shit filled bathrooms. Even with cleaning she got C Diff at her weakest point and was moved to an isolation room. My mother had to clean [the bathroom]. It was black with dirt ... The NHS saved my sister’s life [but] basic hygiene is not something I associate with the NHS. [M3055 f 33 London, compliance manager]

A piece of paper stayed under the bed next to me for over a week. And during that time, there were accidents with bedpans. One patient went home. Another came in. There is no way that ward was clean. [F4125 f 43 County Down, administrative assistant]

Since the NHS began, I and my family have benefited greatly. Now we seem to accept that when we go into hospital we may get an ‘infection’. In fact, only last month, my daughter had a hysterectomy and she caught MRSA. My faith in the NHS has plunged to zero! We are called the ‘sick man of Europe’ by other countries. [H260 f 78 Brentwood Essex, ret shop worker]
I waited 3 months and was very pleased with the treatment I had. However I was in a female ward that had been built as part of an American Forces hospital in WW2. It was linked by stark corridors with the main operating suite in a distant but new part of the hospital. The ward was overcrowded; there was all kinds of equipment stacked on any available space ... The ward was as clean as it could be given the shortage in space and the difficulty in reaching to clean. The staff worked heroically to overcome the difficulties posed by the accommodation and I and the other patients were always treated with dignity. [M1979 f 69 Salisbury, ret local government officer for special needs, having bowel surgery]

[Of a man in his 80's.] The last few months on this earth were made terrible by a hospital super bug. [His niece described dirty lavatory floors, remarking! No wonder people get these bugs when their immune systems are down in the first place. There is the obligatory bottle of hand wash on the way into wards but nobody checks whether these are used or not. [03932 f 41 Workington, long term sick]

The outsourcing of cleaning ... created a situation whereby cleanliness is not the first priority for hospitals. The ... nursing profession perceive [they have] elevated ‘status’ ... where many nurses and midwives refuse to sully themselves with activities which involve cleaning and management of cleaning in wards. They also shy away from cleaning patients ... The more elderly and vulnerable lying in their own mess ... The very essence of the profession of nursing is to care in this way. [S3113 f 34 Scotland, health and safety consultant in NHS, visits lots of hospitals]

One respondent’s friend took a night job with a hospital cleaning company and was ‘horrified at the sheer laziness and lack of responsibility that she found ... from tops of doors that had not been wiped clean for months to the supervisor who greeted the staff with “who is going to perm my hair for me tonight - I’ve brought all the necessary”.’ [H2447 f 73 Oxford, acupuncturist]

‘Bring back ‘Matron’ and the ‘smell of carbolic soap ... Heaven help any nurse, patient or visitor, who stepped ‘OUT OF LINE’. [K798 f 58 Kings Lynn, housewife/student]

On privacy, dignity and quality of care
‘Respect seems to have vanished.’
Many people expressed concern about lack of privacy. Mixed sex toilets and wards were invariably unacceptable. Overcrowding resulted in intimate treatments and conversations being carried out in public space, affecting their own and others’ dignity.

The ward was mixed which I think is disgusting and insensitive. If my bay had been mixed I think I would have died of embarrassment. The sexes had their own toilets but the few bathrooms and showers were for both sexes. There were some male nurses on the ward - they were mainly pleasant and able, but I would have preferred female nurses all the time. [She also described her surgeon as] a pleasant caring man who treated me as a human being and not just as another case [but she was] treated by his colleague with sarcasm. [B89 f 77 Leighton Buzzard, ret audio-typist]

It was also impossible to get any privacy for the 5th person [in a 4 bedded cubicle], especially if they were bed bound as there was no curtain to go round their bed. [F 4125 f 43 County Down, administrative assistant, had kidney transplant in 1997, from a stranger]
In 1998, I spent an entire Friday night in the A and E Department of Hospital, when I had to accompany a friend who was being sectioned under the Mental Health Act. Most shocking of all (for me), as paramedics wheeled an old lady who’d collapsed at home, the one holding her hand called out “Lost her!” At which a nurse literally vaulted over the reception desk, ripping open a plastic sachet containing a primed syringe which she plunged into the patient’s chest, like John Travolta in Pulp Fiction. Twenty seconds or so passed, and the nurse straightened up and said, “No, she’s gone” and the body was wheeled away to the morgue. It took longer to type this than it did to watch it happen.

The medical assessment ward he was sent to was full so he had the first part of his treatment on the ambulance bed in front of the admissions desk. But the staff were kind and apologetic and a bed was soon found, though there was little privacy. We could not fail to overhear a doctor talking to an elderly patient in the next curtained alcove where he was discussing, gently, the options regarding resuscitation should she become even more poorly.

The following morning ‘Dr K’ arrives with SOMBRE looking entourage of about 10 YOUNG DOCTORS. He says in his ‘Dictaphone’, “ a charming lady, bad compound fracture of LEFT ankle, Fracture, blisters, can’t operate for possibly 12 days, HOSPITAL to notify Mrs L’s GP”... As he attempts to walk away, I ask if/when he can operate.” Very bad fractures lady, you will have to stay here until blisters have gone. Can’t operate through blisters. You must be aware of the possibility of INFECTION and possible very restricted movement in left ankle” ... Entourage leaves looking sombre ... All patients must have heard what he said as the curtains were not all round my bed ... I cry.

On standards of care and communication
Many correspondents with similar medical problems had inexplicably varied experiences with different staff in the same ward, and between different wards, in the same hospital and between hospitals. They also referred to insensitive remarks and what might be considered as unprofessional behaviour. The unevenness of experiences with health professionals often tarnished good medical results. These comments are typical.

For my husband coming into ENT clinic that day WAS a big deal - very scary and very unnerving - and they did nothing to allay his fears ... the technician bluntly told him he needed bilateral hearing aids - the shock in his face was huge (has since only dabbled with them). The lesson from this story? If [staff] were more caring in the way they handled [tests] he might now be wearing [hearing aids] ... he’s not and that’s money, time and effort wasted ... Patients are always falling into black holes.

I really cannot fault anything of my referral or treatment, except the surgeon declared he had broken his record for the number of operations in one day! - Somewhere between 24 and 30! I was concerned how tired he and his team were ... The clinic was located in ... Portacabins, which were crowded and gave a poor impression of the standard of care.

We go to hospital because we are ill, but are ... fed the most unpleasant food and come out again to build up our strength with home cooking. Maybe Jamie
Oliver could be persuaded to take on the job of teaching hospital cooks. [F1560 f 87 Carmarthen, ret community/youth worker]

My husband ... got debris in his eye while doing some DIY. The GP treated the infection but did not notice the material ... after 2 weeks with blurred vision ... he went for an eye test. The optician immediately spotted the debris and was incredulous that the GP had missed it and sent him straight to A and E to have it removed ... The treatment he has had at the hospital has been thorough and excellent. [P3213 f 41 Wales, housewife/mother/volcanologist]

I regularly attend the eye clinic [with] glaucoma ... the interval between appointments is 3-12 months so it is rare to see the same person ... Accordingly they each have to start from scratch by reading the notes and examining my eyes. [S3035 m 61 Southwick, ret banker]

[Talking of her husband who died of renal failure in 1997]. He was treated as a person, not a number, and I received wonderful support from all staff on the unit as well. As he chose to have CAPD dialysis, this meant big changes at home and we were looked after by the renal staff who arranged for adaptations in the en-suite, co-ordinated the delivery of dialysing fluid, and visited regularly ... his final weeks were spent in our small local hospital where he was cared for by our GP and a staff of dedicated nurses. I could not have wished for a better end for him. [M2061 f 77 Retford Notts, ret SRN]

Respect seems to have vanished. The old Ward Sisters were rulers of their domain ... Nowadays it’s impossible to identify who is in charge. An Elderly friend had a notice above her bed “Your Nurse is Clare”. When I enquired which nurse was Clare, I was told Clare had left to go and live in Bournemouth three months ago. [G1241 f 75 Frome, ret receptionist/typist at GP surgery].

I was in the same hospital for both operations [colostomy and reverse]. The first was frantically busy and apparently understaffed, so that the staff were unable to prioritise and dashed from one crisis to another, often leaving jobs unfinished. Two patients and I made a complaint of neglect of an 80 year old woman who’d had a leg amputated, who had been left on a commode for 45 minutes in spite of calling for help many times. We were summoned to matron’s office to be interviewed and were more or less fobbed off with excuses; so much for matrons...
being brought in to sort out hospitals ... For my second operation ... I was in a well organised ward, where the care was consistently good, meals were served at regular times. I was still surprised however, that everything came to a halt when consultants did the rounds. This could mean that patients' breakfast got cold while the doctor examined them, but several women were obviously malnourished and food was important. The consultant was usually accompanied by 4 or 5 trainees, one of whom I remember always wore a backpack for some reason. In hindsight this could have been considered unhygienic. [L1691 f 64 Staffordshire, ret probation officer]

The staff were quite friendly but being short staffed we always had to wait for everything. The ward was exceptionally clean - it was mopped about 3 times a day and all the surfaces were rubbed down. There had been an infection in some of the other wards ... The staff worked really hard. People in the ward bonded quite quickly and we all helped each other in whatever way we could. We were treated with dignity most of the time and called by the name we wished to be called by so it was more personal. [J1890 f 76 Hull, ret shopworker, who had recently been in hospital with a liver abscess]

The nurses were sitting and chatting and eating chocolates every time we saw them. That air of quiet efficiency that used to pervade hospitals had entirely gone. In contrast my mother was in two hospitals in Gloucestershire last year and we were very impressed with quality of the nursing. One of the hospitals had been much criticised in the press for its care of the elderly, but we couldn’t fault it. I felt that my mother was treated with dignity at all times. [R1025 f 65 Milton Keynes, housewife, on her aunt’s hospital care]

On people’s experiences of private care

‘Nobody in their right mind wants to go back to the days when medical treatment was an unaffordable luxury.’

In 1997, a few correspondents had private insurance, mainly through work, or had resorted to the private system because of delays in getting an NHS appointment, or for a second opinion. The benefits were swift access, sometimes to see the same consultant they would have seen in the NHS, and what they deemed as more appropriate care.

I did go to a private consultation to a doctor some 7 years ago because the waiting list was so long - I was admitted at once to a BUPA clinic and was given good care, then on to an NHS hospital for an opp on my spine and the care was just as good. [B1424 f 73 Swanley, ret office worker and telephonist]

My younger daughter has suffered from back trouble for years but has invariably been fobbed off with platitudes at hospitals. Eventually a private osteopath discovered she had a curvature of the spine. [B89 f 66 Leighton Buzzard, ret typist]

Recently, a retired friend aged about 70, in the suburbs of London was taken ill at home, confined to bed and unable to do anything. Her GP suggested bed rest. When she did not improve the patient’s companion talked to the GP and he as good as said nothing could be done at her age. The patient paid £400 ... saw a rheumatologist privately and was treated and is now fine. [B2154 f 64, small town in Gloucs, ret radiographer]

By 2008, people felt the costs of private care were being ratcheted up. Insurance conditions seemed to be tightening. On the whole, correspondents found standards in the private sector good, but lack of aftercare from private hospitals was frequently cited as a problem. There was much soul searching about the morality of
private care. Some felt compromised into using private care because of rationing of a particular health treatment on the NHS and the ‘post-code lottery’. The following quotes illustrate many people’s experiences.

*I had a problem with my hearing … the wait to see a specialist … was … at least 6 months … I was in constant distress … Against all my principles, [I went] private and [was seen by the same specialist] in a matter of days.* [P3213 f 41 Wales, housewife/mother/volcanologist]

*I’ve had peripheral cataracts in my eyes for at least 25 years which haven’t bothered me very much. Recently, however, my sight has deteriorated a lot … I needed surgery to replace the lens in both eyes. The NHS apparently doesn’t deal with my sort of problem. As it was unlikely I’d meet its strict guidelines for treatment for several more years, it was suggested to me that I should have the surgery privately. I did earlier this month … I was delighted by my treatment. I was at the hospital … for a total of two and a quarter hours; the actual surgery took just 30 minutes (both eyes done), followed by a welcome cup of tea and biscuits in my room with my husband. Extremely impressed! Only complaint was the bill, which was almost twice the estimate given by my optician from last private patient before the BUPA hospital was taken over.* [M388 f 77 Morpeth, former lecturer, wife of retired GP, her emphasis]

*I did not receive an appointment from the hospital in the statutory ten days time, so I turned to my health insurance [which] does not cover operations for breast cancer, but would meet the cost of 2 examinations and diagnostic procedures, so I went off to a private hospital in Brentwood. The upshot was that I did have a lump, and needed an operation which the surgeon was willing to perform on the NHS at the hospital where my husband was misdiagnosed and died under horrid circumstances. I couldn’t bear the thought of going there, and chose instead to pay for private treatment by the same surgeon … Two days later I was operated on, and home after two days and £3000 poorer after that. I attended outpatients’ appointments at X Hospital and had radiotherapy at Y Hospital, neither of which are as badly run as the private hospital where I had my initial diagnosis and operation. It is time someone sat down and worked out a realistic assessment of what we can afford and how we can pay it.* [R1760 f 77 SW Essex, ret civil servant, her emphasis]

*Private consultants see us as cash cows … no matter what they promise at the previous consultation, they always go back on it wanting to ‘try something else first’ … costing £1500 a time.* [P3373 f 34 Wales, police officer, husband with chronic condition]

*I have never had any private care. I fundamentally disapprove of it. Why should people who pay jump the queue? If we all had to wait the same amount of time, perhaps the service would be quicker. Having said that, as far as my own treatment has been concerned, everything has happened with almost alarming speed. My father had an angioplasty done privately in Harley Street some years ago. The care there was quite appalling. He had to lie flat on his back for a while and was brought a meal that was just left there and he couldn’t reach it. My daughter was visiting and ended up feeding him. They were cavalier when he was leaving hospital and seemed to be quite uncaring. So perhaps private health care has a lot to learn too.* [R1227 f 63 Near Exeter, teacher, has had melanoma and breast cancer and husband has Parkinson’s Disease, at 61]

*I feel the introduction of the private sector into hospitals has had a very detrimental effect on the patients’ health and also the cost of treating people. Drugs companies take a lot of money with very expensive drugs which has
resulted in treatment for various conditions being a post-code lottery … The whole system is fractured beyond compare and the Governments’ performance in the headless chicken department deserves an Oscar. [03932 f 41 Workington, ex shorthand typist with MS]

My eyes were so scarred by 5 years without treatment that [the NHS consultant] pronounced the condition untreatable. If treatment [with Lucentis] had been possible it would have cost £1000 minimum per injection - about 6 needed ... No wonder people go privately if they possibly can ... Blindness renders me incapable of cutting my toe-nails which need attention every 5 weeks. However, the NHS chiropodist will not treat me because I use a private chiropodist in between. Covering their backs. [N 1592 f 76 Hebden Bridge, ret landlady, counsellor, registered blind]

The morality whereby money can buy better treatment is the subject of debate, but by working hard all my life I was in the position to buy treatment, and that ability is in part due to hard work that would not be the case if all was equal and free. My policy came through my employer, partly a perk, but also to ensure that key employees, plus me, were away from work for as short as possible. Until the NHS can guarantee a level of performance as high as the private sector, companies will provide the funding for their employees and better off people will pay from their own resources. This is the 21st century, and the thinking should be for the 22nd, not as at present 19th century thinking ... So ends my Philippic. [R3422 61 Brentwood, ret banker]

All Government ministers should be required to use the NHS and not private medical care. [B1386 f 55 Oswestry, telephone copy taker]

Summary
People’s expectations were low when the NHS began in the 1940s, and the hospital service was particularly appreciated by MO correspondents. By 1997, long term underinvestment had resulted in many dilapidated hospitals and staff shortages. Government policies that put more management into the service had resulted in professionals feeling their values were being undermined and marginalised. Correspondents wanted more money on the front line. By 2008, the hints in 1997 that hospital cleanliness was a worry became a clamour. Most people cited it as a major concern and many had horror stories. Standards of care, attention to dignity and communication were variable. Nurses, who had previously been idealised, were often cited as delivering indifferent care. People tended to use private care to circumvent delays or deficits, rather than out of principle. In 2008, there were signs that use of private care was less, with evidence that people were experiencing shorter waits for NHS surgery. The general situation was summed up by one correspondent:

Over many long years there has been a definite improvement in treatments, waiting lists and patients rights. But a deterioration in cleanliness, friendliness and nutrition. [R3032 m 66 Cardiff, ret civil servant]
Part I

2 General Practice

'I sincerely hope that I never need to see a doctor urgently.'

From its inception, general practice has been the most contentious area of the NHS. It was only at the 11th hour, in 1948, that GPs voted to join the NHS, so the transition from private practice and a system of ‘panel’ doctors for those covered by government insurance (mostly employed men), was unplanned. The arrogance of many doctors pre-NHS, and their preoccupation with payment, was satirised in an MO publication of 1949, Meet Yourself at the Doctors.

Patient: Doctor, what I need is something to stir me up - something to put me in fighting trim. Have you put anything like that in the prescription?

Doctor: No, you will find that in my bill.

1949, General practice at the start of the NHS

In 1949, a mixed picture of general practice was presented by MO correspondents.

My] Doctor [is] busier than ever, it seemed, but gave me excellent and thorough treatment, including 5 X-ray photos, all free of course. [237 m 28 research worker]

[A 21 year old married man describes his first visit to an NHS GP in London. He waits an hour and ten minutes] ‘In a shocking little basement level waiting room heated by a smelly oil-stove. The Doctor said “good morning” and “next please” to each one with a smile. Patients were made to feel that the Doctor was very pleased to see them.’ [4572 m 21 bank clerk]

[A man of 27 who has recovered from TB describes his GP as] ‘a completely useless man, I don’t suppose he’s learned anything in the last 25 years ... Everyone with TB I have known always says GPs know practically nothing about the disease at all. They are all right for indigestion, colds, or a not too difficult childbirth’. [1040 m 27 mechanical engineer]

[The Doctor visits but] ‘he does not like the scheme and says so, but he appears to remember the oath of Hippocrates’. [0190 m civil servant]

Doctors have largely appeared to me as more arrogant than most professional men - with less reason! [4428 m editorial assistant]

I am lucky in having a keen socialist, who is anxious to help his patients. [1666 f 51 housewife]

1997, the NHS at 50

‘Now if you phone after hours or weekends you have to go to the GP centre in our local hospital.’

By 1997, many older correspondents who reminisced tended to have fond memories of the GP services at the beginning of the NHS. They tracked changes over 50 years and appeared long-suffering about shortfalls in the contemporary services. Recall is particularly important because it shapes their perceptions, irrespective of whether it is strictly historically accurate. Across the age groups, public demand and expectations were demonstrably increasing and problems were emerging.
To be fair to our Doctor he at once put father [who had broken his leg pre NHS] on ‘The Panel’ which helped, but the leg he splintered on the kitchen table … I also had my tonsils operated on the same kitchen table. When we three children had whooping cough the only cure was to stand near a steam roller when tarring a road. [H1709 f 83 Oswestry, ret farmer]

When the NHS began in 1948, although not fully ‘Beveridge’, it still held promises of ‘cradle to grave’ medical care and was poised to bestow free teeth and free glasses to all who desired them. And what a vast change came over our hospitals and doctors surgeries. Gone almost overnight were the penny pinching, brusque treatments of the old panel system. Doctors were known to smile at their patients and be almost human. Very soon the politicians were telling us our health service was “the envy of the world”. Maybe it was. All I can remember about those early days was this vast change for the better. [R1418 m 75 Derby, ret decorator]

When we first went to [the GP] 18 years ago, two practices shared an old house and we sat (and stood) in a cramped waiting room. At least they had an appointment system. I can still remember in the sixties and seventies waiting for the doctor with 4 children about me -sometimes for hours. The only good thing is that they usually came out when you phoned ... Now if you phone after hours or weekends you have to go to the GP centre in our local hospital. [A1473 f 66 Lincoln, housewife]

Over the last 20+ years I worked, I saw the demand grow, more demands made for more minor problems, as well as an increase in such instances as asthma and cancer ... particularly following the Patients Charter. [She goes on to describe a woman who wanted ‘nit’ lotion that used to be routinely given.] The patient thumped on the desk and said that as a person on family income supplement, she had a God-given right to be given whatever she asked for. Unfortunately, many patients do seem to have this view of the GP surgery. [G1241 m 63 Frome, ret dispenser at fund-holding GP practice]
2008, the NHS at 60
‘It used to be much easier to get an appointment.’

By 2008, the national policy shift from hospitals to community-based health care, placed even greater emphasis on general practice. MO correspondents were becoming aware of the difficulties caused by escalating public demand.

I do believe in the ideas of the NHS (I have worked in it for 11 years) but it was set up where there was full employment, and an extended family unit etc. It has had to alter and expand its role, which has made it more difficult and expensive to run. [Y296 f 49 Newark, clerk with GP fund-holder/ward clerk, care of elderly]

The way services were being delivered was changing too. The target culture, the focus on accounting for the provision of specified services (such as for diabetes and heart disease), affected the experience and perceptions of many people in the surgery. Few people mentioned polyclinics. Despite government policies to improve appointment systems, they remained the focus of many correspondents’ complaints, along with the out of hours (OOH) services. Little mention was made of NHS Direct, and when it was referred to, reports were mixed about its helpfulness, but complaints were usually linked to experiences of the OOH service.

At around 7.30 on Friday evening, I experienced the most excruciating pain in my right side. No warning: straight into a 9.5 on a scale of 1 to 10; shouting and swearing, much to the alarm of the cat! [After phoning back and forth to NHS Direct] … They could offer no diagnosis, but suggested I make my way to the out-of-hours clinic, a couple of miles away. They did not seem to understand that I was in no state to drive, but I did get a neighbour to drive me there. [R3032 m 66 Cardiff, ret civil servant]

Older people, in particular, were unable to fathom why appointments had become more complicated, when 30 years ago ‘you could just turn up and see a GP within an hour’, and now have to wait ‘a fortnight for a named GP’. [C3603] Generally, when people did manage to see their own doctor, they were complimentary about their care. An 89 year old man describes the situation of many people:

Some years ago the arrangements for appointments were [that] you could only see the doctor on the day that you phoned. It used to be much easier to make an appointment- you phoned and spoke to someone without any delay … and could see your doctor at a future date if necessary … Now, phone calls seem to go to a number that isn’t real, and you get a whole rigmarole of a preamble from an automatic answering machine and then are put in a queue for an actual person … all very impersonal and inconvenient. I sincerely hope that I never need to see a doctor urgently … It used to be a great deal more convenient and simple. [G2134 m 89 Cheam, ret civil servant]

Some practices were making strides to improve access. For example, ‘nightmare booking systems have been transformed by the introduction of touch screen monitors’, which also meant ‘you don’t have to face the arrogance of the booking staff’ [F218]. ‘Evening surgery provision was still patchy, many only just starting up’ [F4125]. Occasionally, people mentioned appointments to see nurses instead of ‘waiting for up to 2 hours’ for a GP [I1616]. Not all innovations were working. For instance, appointments that are only given after the doctor rings to decide whether the patient really needs one, ‘means waiting by the phone, sometimes nearly all day’ [L1691].

‘In the old days … we would have seen the same GP from cradle to grave.’
Though there were isolated poor relationships between patients and doctors such as S1399 who had breast cancer in 1996, and a brain tumour in 2004, and
thought her symptoms were missed by her GP, describing him as ‘ABYSMAL’, correspondents generally portrayed relationships with their GP as ‘good and sensitive’ [N403, B2969]. The main concerns were about continuity of care, a lack of ‘joined up services’ and problems about conditions being looked at ‘in isolation, of not being seen as a whole person’. A number of correspondents mentioned hating doctors’ preoccupation with the computer screen. Many lamented the end of home visits, even for people who ‘could hardly walk’. [S2207]

I hate the way doctors sit and read the computer screen instead of facing me, giving me their attention. In the old days this wouldn’t have been necessary as we would have the same GP from cradle to grave ... Now they don’t even have to familiarise themselves with our medical history ... I feel it is impersonal. [K798 f 58 Kings Lynn, housewife/student]

When I moved to Cambridge, I was put on the doctors list and was given a thorough check up. It was found I had type 2 diabetes, irregular heart beat and now tinnitus. So my relationship with doctors and staff at my health centre is very good. [N403 f 71 Cambridge, cleaner]

I hate going to my GP as I feel there is a complete lack of joined up services. Each time you go in, they look at you as new and your problem in isolation. If I had done this as an OT I would have been struck off. My friend who has Graves’s disease found this out recently when she was put on medication which was detrimental to another condition that she had, and the GP had not looked beyond the problem he was facing. They get paid huge amounts of money but miss the basics. [J2891 f 43 N Wales, previously occupational therapist, now working in admin for a charity]

‘GPs do [not do] OUT of HOURS but [have] handed all the responsibility to a NHS call centre surgery somewhere miles away.’
The original NHS system where individual GPs were on call 24/7 has been eroded over 60 years, though even in the 1980s the system was still in operation, impacting on family life, as a GP’s wife recollects.

From a family point of view ... every third night [with partners] and weekends he was on call. No mobile phones at that time meant I was also on call to receive and relay messages. Whilst I could appreciate that for some patients, this was a wonderful service, I was very much confined to the house. [M3412 f 48 North Cave, teacher]

By 2008, these partnership arrangements had evolved through cooperatives of local GPs into the new contract, where GPs could opt out of OOH delivery. There was the odd affirmative story about the service.

I had to call a doctor out on a Sunday afternoon 3 weeks ago. She was so kind, understanding, and gentle (and arrived so quickly after I had made the call). She asked my husband, “Do you want to go to hospital?” and then asked me if I wanted that. Getting a firm “No” from both of us, she said she would call out again if his condition worsened, or [we] could dial 999 and get him admitted. [P2546 f 82 Hereford, husband, 97, died last month]

However, most people were mystified and unimpressed by the remoteness of the OOH services. They complained of having to travel unacceptable distances and of the inappropriateness of advice, because the doctor did not know them. It was in the context of the failure in the continuity of GP services, that criticisms of GPs working hours and pay crept in. The following stories are widespread and typical.
Out of hours services ... are a farce. You are connected to a ‘professional’ health care worker or doctor via a telephone. You the untrained are trying to describe medical signs and symptoms to a person who you cannot see or they cannot see you. Diagnosis based on worried people’s possible exaggeration or omissions of facts. Hence wrong diagnosis and more resources wasted. [A4127 m 45 Nantwich, unemployed, referring to experiences with his parents]

[This story is about a 96 year old woman, who lived with her daughter.] I told our GP – he is a likeable man ... I looked him straight in the eye and said, “If I were earning what you are earning I would feel it was my duty to be on call to visit”. He explained the GPs as with hospitals had stopped all home visits, and did not do OUT of HOURS but had handed all the responsibility to an NHS call centre surgery somewhere in DERBY!!! Everyone I know is amazed GPs can do this. They are paid too well ... Evening call out and SATURDAY surgeries should be re-instated and GPs should be more accessible. The result of the present situation is that folk ring 999 and the poor DOCTORS in A and E have to cope with babies with a ‘RASH’ and elderly patients who may only need reassurance. The A and E departments can’t cope and the GPs are putting their ‘feet up’. SHAMEFULL!! [L1002 f 61 Rochester, Staffordshire, ret shop worker, correspondent’s emphasis]

Summary
At the beginning of the NHS, public expectations of general practice were low. The removal of payment for services was such a relief that any service was appreciated. By 1997, expectations had changed, but generally the personal relationships with GPs had kept pace with them. Responses in 2008 presented a different picture. The public, who were often better informed through the media and internet, were expecting a more dynamic, responsive and accessible service but instead they experienced the complex appointment schemes, remote out of hours services and discontinuities in the doctor - patient relationship as a poorer service. Where people were able to see their regular GP they were usually satisfied.
Part I

3 For better, for worse? Childbirth and maternity services
‘There were ten days’ confinement in my day; now you are sent packing as soon as you can stand.’

In writing about birth experiences however long ago, MO correspondents vividly recalled the details. The drama of it became part of family history for women who compare their own experience with that of their mother or daughter. And where women had had more than one child they were able to compare the births. Some men, now that they were present at the birth of their child, wrote about their involvement in the process. Whether the birth was at hospital or at home, the correspondents’ accounts of care ranged from excellent to appalling. While childbirth has become technically safer, short hospital stays, lack of cleanliness and a shortage of midwives have more recently marred an otherwise good experience.

Memories of the birth experience and comparisons over the generations

[Mrs. Lamb was born in 1946, describing herself as ‘a child of the NHS’ She might well not have survived her mother’s toxaemia, had not her father insisted his wife be sent to a private hospital.] “Your wife is not the only pregnant lady in Ashbourne,” [said the reluctant GP] “I know,” replied her father, [who had recently returned from war service as a medical orderly,] “but if anything goes wrong at this late stage, I shall know who to blame.” [After a month in hospital the baby was safely born and family history was made. Mrs. Lamb’s own daughter had a baby in 2000. When she wrote about this experience in 2008, she reflected that]: ‘Childbirth. This is a lottery. I think the main thing I have to say here is that CLEANLINESS OR LACK OF IT is the worrying aspect here.’ [L1002 f 61 Staffs, ret shop worker, her emphasis]

[In 1997 Ms Baker, pregnant with her second child, described the difference from conditions when her first child was born at home in 1977.] ‘There is a lack of time and space now for explaining issues and patients’ requests. Now paper nighties and towels, two to three days in hospital; then nine to ten days.’ [B2031 f 37 Plumstead Surrey, former environmental services manager]

‘There was ten days’ confinement in my day; now you are sent packing as soon as you can stand.’ [In 1997 Mrs. Brown, then in her late 50s, reporting on the recent birth of her twin grandchildren, did however praise the health visitor for putting her daughter in touch with a very supportive Twins Club. Her own experience of childbirth in the 1960s had been mixed. Two daughters were born in hospital.] ‘My experience in maternity was merry. We had auxiliary staff to bring us water and toothbrush, a physio to get us back into shape and the midwives to have a laugh with … We got our own tea and washed up. We weren’t ill. The food was wholesome and free but not particularly good - some grumbled.’ The third daughter was born at home where everything had to be paid for and the midwife arrived only just in time. When the doctor called a few days later, ‘he admired my husband asleep on the bed, and collected his fee. I don’t think he looked at the child or me.’ By 2008 Mrs. Brown has a new

* These names are fictitious
grandchild delivered by emergency caesarean in ‘Our local NHS hospital [which] is top in the County for Maternity. This is endorsed by every mother lucky enough to produce there. The staff are just lovely according to legend and the follow-up at home [but] premature triplets had to be driven miles for treatment in three different units.’ [B1180 f 69 south coast, ret clerk]

[Ms Craigie writes from the Shetlands in 1997 about the hospital birth of her first baby in 1985 and her campaigning for home births] ... ‘I wanted a birth under the Domino scheme. This should have meant going into hospital with my own midwife and staying in for four hours. I didn’t get what I wanted and ended up staying in for nearly five days. Since then I have had three home births, not wishing to repeat the experience of a hospital birth ... I hear of terrible experiences of friends and acquaintances who suffer at the hands of the NHS. Handling of home births has been appalling in the past. They have recently changed their guidelines in the light of the Winterton Report. [See notes.] It remains to be seen if this changes anything. I feel powerless to change things, although I continue to complain about provision for home births.’ [C41 f 37 Shetland, single parent, home educator and student of homeopathy]

By 2008, home births were still not universally encouraged by clinicians. Mr. Howard describes the home births of his two children, now aged six and four. Despite possible complications identified during scans for the first pregnancy, a home birth was allowed to go ahead by the gynaecologist:

‘It felt like we were doing something counter-cultural.’ [Both births were managed by the same excellent midwife] ‘a strong looking Yorkshire woman ... she looked like she could jump over things.’ [When there was a worrying delay during the second birth she] ‘leaned in like a boxing coach and urged K on to something extra – and we were over that ... Two babies – a boy and a girl. Those memories are part of my fabric.’ [H4234 m 37 Leeds, cultural sector consultant]

[Mrs. Connell compares maternity services in 1997 favourably with the 1950s when she had her children. In particular, she remembers the emergency dash by helicopter to a Glasgow hospital after a haemorrhage following a home birth.] ‘I “died” three times ... lay in a strange hospital and no-one had any information about me. ... I think maternity now is a completely different set up. The fathers take part for one thing ... Also women aren’t treated like cows and silly remarks like “see you next year” or “I see you’re practising for the world record in child bearing.” Just because you come from Ireland doesn’t mean you want or could produce a child every year of your productive life. Now, each woman is given a health visitor who gets to know her and what she requires. It is now recognized that child bearing is hard work and could be dangerous if not handled properly.’ [C1191 f 42 Limavady Northern Ireland, full time housewife, carer]

The practice of midwifery and the patient:
‘We learnt to care more over the years but it is possible that situations like these will return.’

MO correspondents had heartbreaking memories of the poverty and squalor amidst which some midwives and nurses worked both before the NHS and in its early years. Professionals were put in difficult ethical positions, for example in making decisions about sustaining the life of deformed babies. In the 1950s, nursing attitudes towards pregnant women and those who had suffered an abortion was sometimes described negatively. But as social conditions and medical technology improved, midwives were subjected to different pressures. Lack of staff and higher expectations by patients led to a perception of a hands-off, less caring profession,
though there were always shining exceptions. By 2008, continuity of care and being confident enough to express birthing preferences were regarded by MO correspondents as important aspects of a good experience.

[Mrs Adams, born in 1942, recalls in 1997 how her mother, working as a district nurse and midwife in London before the NHS began] ‘suffered agonies about the poor and their health … She of course could remember delivering babies on newspaper in the slums around Charing Cross Hospital, then in the Strand. This was in the 1920s and 1930s. Some babies were even wrapped in newspaper in cold weather. She told me they used to put a pillow over very deformed children and say they were still-born. It was then considered the most humane thing to do. When the poor had a baby every year – and few survived – they had no time, money or public facilities for handicapped children.’ [In the early 1950s as a school girl, Mrs A went with her mother in the holidays to visit her ‘patch’ around Cleveland Street. She remembered] ‘a totally crippled mother in a room about 12 feet by 12 feet on the fourth floor of a crumbling building … She had four children. Three slept in a double bed, she and the youngest in a single. They had a small table and a cupboard. That was home … Every day the eldest boy went home at lunch to carry his mother’s slop pail/potty down three flights to the lav. She always smiled – her only lifeline a weekly visit from the health visitor … We learnt to care more over the years but it is possible that situations like these will return.’ [A1473 f 54 Lincoln, dinner lady supervisor, former teacher]

For Mrs. Bird looking back from 2008, caring did not seem to be high on the maternity nursing agenda in the 1950s. She wrote, ‘Comparing my recent hospital experiences with my first in 1958 when I spent weeks in another hospital with pregnancy troubles, the present is like a pleasant dream compared to the nightmare of those days. The sisters were generally harsh martinetts, the wards huge and bleak and there were plenty of infections, which could be dealt with quickly by antibiotics. Nowadays the infections are more resistant to penicillin etc. The matron kept a firm eye on tidy beds but was rather economical with kindness.’ [B89 f 77 Leighton Buzzard, ret typist]

In contrast, Mrs. Bryant, writing in 2008, had had a very good experience in the 1950s. ‘When I had my first child in 1958 in South London Hospital for Women, things were very different. Nurses and orderlies were in abundance. Maternity stay was 10 days plus I had been in a week before the birth because of high blood pressure.’ The birth of her grandson in 2007 by caesarean compared less well in some respects. ‘She [the mother] had very good care but no hot food – only sandwiches. I think that is poor (treatment) for young mums.’ [B1771 f 72 Mitcham Surrey, ret secretary]
Mrs. Ainsworth wrote in 2008 that ‘In 1957 before the [Abortion] Act, I nearly died and I think the practice of putting miscarrying, aborting, partial birth mothers in the same ward is unfortunate. Some want their babies and some don’t. It should be a woman’s right to choose.’ However she later had a very good experience. ‘I had my second child at home; it was wonderful and the midwife perfect. It is a shame that midwives are now so scarce and mistreated; poor pay was always for nurses but at least they had status and some perks; not now.’ [A1292 f 75 Croydon, grandmother, p/t teacher]

‘I feel we have lost some of the dignity, both in staff and their attitude to patients’ says Mrs. Batchelor in 2008 about her fifty years of experience as a midwife and practice nurse and as a patient. She had also written about her experiences in 1997, [as did over a third of the 2008 correspondents], when she had just retired after working her whole life in the NHS. She still remembered the stress in her early days as a midwife of having to make decisions about severely deformed babies and then break the news to the parents. But by 2008 she acknowledges the great improvements in maternity services in Grimsby where she lives, which now has ‘state of the art maternity, paediatric and neonatal units, antenatal and gynaecological out patients’. [B2552 f 76 Grimsby, ret nurse/midwife]

Ms Holmes perceived that a ‘great deterioration in the NHS is in the lack of professionalism and serious carelessness amongst nurses’ [with many including midwives being] ‘grossly overworked.’ She wrote in 2008 that a colleague attending a birth witnessed: ‘One midwife saying to another with a newly delivered mother present, waiting to have stitches: “I wouldn’t want to be stitched by me”, as they argued about who should do it.’ [H2447 f 73 Oxford, acupuncturist]

Mrs. Gerant wrote in 2008 of the shortages in the maternity unit where she had been delivered so that she only had one midwife when the unit was very busy. She understood the hospital could not afford more and one night the unit had to be closed with patients being diverted to other hospitals:

That doesn’t bode well for the future’ [she thought. However she was full of praise for her own treatment] ‘My experience of pre/post natal care and childbirth on the NHS is extremely positive – I had two fantastic, lovely midwives during both pregnancies, four years apart (the same midwives), and the same health visitor. I was given the pain relief I wanted during childbirth, and the midwives present during my first delivery were fantastic. The second time I didn’t like the midwife, she was very ‘dry’...and tried to talk me out of having the epidural I wanted. I think if I’d been a young girl, I’d have been intimidated into doing things her way, but being the bossy, determined, opinionated woman I am, I made sure I got what I wanted. [G3963 f 35 North Wales, housewife, mum, formerly a construction tax specialist]

Lack of cleanliness in maternity wards
‘I was horrified at the carelessness in cleaning I saw ... It seems that there is no real understanding of what true hygiene is.’
The lack of cleanliness in maternity units was one of the most frequent concerns in 2008 with many vivid descriptions to illustrate the accounts of correspondents, although this had appeared as a problem from the 1980s onwards.

When she wrote in 1997, Ms Brice, a woman in her 40s, gave a detailed comparative account of her four caesarean births at the same London hospital between 1979 and 1986. Cleanliness did not appear to be a concern until her
third birth in 1984, when she described the cleaning as ‘much less but still adequate’. By 1986 she was calling the cleaning ‘inadequate’.

Ms Brice continued to monitor conditions in the hospital from 1988 to 1993 through a National Childbirth Trust support group she ran in Hackney, East London. She observes: ‘Over this period conditions grew steadily worse; lack of provision to the extent of having no linens, nothing clean for new babies including no nappies, cleanliness dreadful so that we were told to recommend new mothers to bring scouring equipment and disinfectant with them and my mums were actually having to clean baths/toilets etc themselves before use. Wards were cleaned but rarely (compared to two or three times daily in my first delivery visit), once a week even!’ [B2197 f 42 formerly London (emigrated), mother, housewife, volunteer librarian]

Ms Hardwick comments in 2008, when the state of maternity wards seems even worse: ‘One complaint I often hear is the lack of cleanliness in hospitals.’ She goes on to describe her daughter’s labour a few years ago in a new maternity unit in a south London hospital. ‘I was horrified at the carelessness in cleaning I saw’ … ‘There was no actual dirt to see but the floor was of a pimpled texture, probably to stop anyone slipping, but a complete germ trap.’ [When the cleaner came in] ‘this consisted of slopping a mop around the floor in a desultory fashion from a mop bucket of dirty water, and wiping round the birthing pool … Hospitals more than anywhere should be aware of thorough cleaning and disinfecting procedures.’[She is also critical of alcohol rubs rather than hand washing] ‘which is far more effective. It seems that there is no real understanding of what true hygiene is. I believe the contracting out to private companies of cleaning services was a very backward step, with workers poorly paid and with little or no pride in their work, as the former in-house employees used to feel.’ [H2447 f 73 Oxford, acupuncturist]

Also in 2008 Mrs Lamb, relating her daughter’s experience in a Derby hospital in 2000, writes with emphasis: ‘The main concern my daughter had was the lack of cleanliness everywhere.’ [In the shower room, where mothers took their babies in cots because of a previous baby snatch] ‘I was amazed, the floor was dirty. There was BLOOD on the TOILET floor, before she used it. It wasn’t her blood … It was horrible and the BATHROOMS needed a GOOD CLEAN!’ … Fortunately when Mrs. Lamb’s daughter had her second baby in another hospital in 2006 conditions were much better. But looking back Mrs. L sees a reason for the problems with keeping hospitals clean: ‘On the whole the problem with MRSA and C.Diff. are as a result of years of cutbacks in cleaning services. When in 1990 N.U.R.E. warned of a cleanliness disaster because cleaning had been “put out to tender,” I knew it would result in disaster. Cheapest is not the best. Contract cleaners are not being told directly what to do by the ward sister. Indeed ward sisters have only just reappeared as a force for good’. She contrasts this with a hospital she visited in 1961: ‘The smell was of carbolic soap and cleanliness, a ward sister sat at a desk in the middle of the ward and heaven help any nurse, patient or visitor who stepped out of line.’ [L1002 f 61 Staffs, ret shop worker; her emphases]

Mrs Aston’s experience, described in 2008, was grim. ‘Although I took antiseptic wipes I went home in my dirty nightdress because the bathrooms were just too filthy to get changed in. I managed to get myself discharged earlier than normal after a c-section by arguing that at home the environment was cleaner and the patient:carer ratio was better.’ [A3434 f 43 Winchester, ret 2003 from UK stockmarket to take care of her son]

Not all examples are of poor hygiene standards. Mrs Bryant, whom we have encountered before, describes her daughter’s emergency caesarean in 2008:
Communication, continuity of care and ‘being in control’

‘Seven years on it now seems a “blur” – but now and then it all floods back and hurts so much.’

In 2008, Mrs Aston recorded the birth of her son, now aged four, in a central London hospital. Because she was on the edge of the hospital’s catchment area, she received less care before and after the birth, which she conceded was ‘a good example of on the ground prioritisation.’

However: ‘the result was that there was no continuity or consistency in the care I received – I never saw the same midwife twice. When I toured the labour wards the head of the unit warned us that everything would be done for us and our baby until we were safe and sound but that post natal care was absolutely non existent – we were told to bring our own antiseptic – because limited funds had to be allocated at the sharp end… I was induced and had a fairly tricky time ending in a C-section but I always felt safe and that we were in good hands. Once out of the HDU [high dependency unit] 24 hours later I understood about the lack of funds. The post natal ward was full – 40 beds with at least 40 babies – and only two midwives on duty at any one time. I was lucky as I had a lot of support but nevertheless it was an alarming period and place and it felt very lonely – must have been a lot worse for others with less support’. [A3434 f 43 Winchester, ret stockbroker]

The birth of Mr Crown’s son was traumatic. Writing in 2008, seven years after the event, he describes the old hospital and ‘a dirty tower block – understaffed and with an emergency system that failed.’ After a 24 hour labour with four different midwives, his wife had an emergency caesarean with 20 minutes to save the baby. ‘The doctor then shoved [the baby] at my wife and said abruptly: “He’s got Downs and no bottom.” The next three weeks was hell. I was called in at 4am – my wife was isolated in tears/shock/pain – junior was put into “intensive care” … Seven years on it now seems a blur – but now and then it all floods back and hurts so much. For six months it was a rollercoaster of daily visits – trying to park – trying to work – trying to keep on an even keel.’ Mr. C’s wife failed to receive any help for her distress despite appeals to her GP and he was left to cope with the subsequent years of operations and problems with his son’s care. [C4102 m 43 Norfolk, self employed, family member and carer, his emphasis]

Mrs Avery, a young mother of two children and expecting a third, writes in 2008 that she has also seen a change for the worse in maternity services over the past five or six years, with less funding to provide contact with a midwife than in her earlier pregnancies. In 2007, when attending a 13 week scan ‘the sonographer bluntly told me: “Your baby is dead.” There was no consulting a doctor or words of sympathy. Instead I was bluntly dismissed and informed someone would contact me later. At home I was unable to contact a midwife and it was only due to intervention from my doctor that I found anything out. The early pregnancy assessment unit contacted me the next day (Friday) and I was disgusted to be told I would have to wait 4 days for a procedure to remove the foetus. It was down to immense pressure from myself that I managed to be admitted that day instead. The care and attention I received in regards to this procedure though was faultless. The staff were very compassionate and informative and ensured I received information in regards to the procedure and support groups in my area. A porter even waited with me prior to the operation
to console and comfort me. My primary complaint was, and still is, with the sonographer and her lack of tact. At this moment in time I am 14 weeks pregnant and yet no effort has been made to increase my antenatal care. When I asked my midwife about this she informed me that a shortage of finance had resulted in the changes in care. I think the NHS do a fantastic job but it is often a case of “overworked and underpaid”. There is a severe lack of funding which has dangerous repercussions.’ [A3961 f 26 Arnold Nottingham, homemaker]

Ms Brice [see earlier, who had four caesareans and was able to get feedback from the young mothers she supported at the local the National Childbirth Trust from 1988 to 1993], reported in 1997 that patients were becoming more critical of health care, partly she thought through American influence. However ‘at the same time many people are very docile and often they don’t want to know – the benefit of the doctor is that he takes over … I saw the misery on many occasions of Caesarean mothers who felt ill-informed or completely left out of the decision who were still feeling abused years later. I don’t think doctors like to be challenged … The team spirit began to grow in the 1980s but lack of funding soon put this under pressure and in many areas it died out.’ [B2197 f 42]

Writing in 2008 during the 34th week of her pregnancy, Mrs Jones describes the mixed experiences which are typical of so many MO reports. Her GP had, she felt, been less than helpful but she was full of praise for her antenatal services which have been ‘thorough, professional, informative and supportive.’ She is attending two antenatal courses, one with her husband at the hospital and one in the community. ‘The midwife and physiotherapist at each session show dedication, passion and professionalism … I am impressed also that the government has given the NHS the resources to do this and although it is obvious that the midwives are stretched and we need more of them I am so impressed by the holistic and thorough support my PCT [primary care trust] has given me.’ But she knows that not all PCTs can do this and also wonders how it is for younger single parents coming to these classes. ‘I know through my job that teenage parents get specialist support through Sure Start plus – however with much of the funding finishing for this support I wonder where this leaves support for vulnerable groups.’ [J4051 f 32 Leeds]

Summary
For parents the birth of each child is a special event which is rarely forgotten even decades later. The quality of the care received whether excellent, inadequate or somewhere in between, is described by MO correspondents in well remembered detail. As fathers have become much more involved their accounts are informative, as are those of grandmothers, comparing their experiences with those of their daughters.

Many MO reports raise concerns about care, cleanliness and communication in maternity services. Nostalgia about ‘the good old days’ of clean well disciplined maternity wards is balanced by other memories of harsh conditions for the poor. Experience of home births has varied greatly over 60 years and, as caesareans have become more common, issues around consultation and being in control arise. There are reports of outstanding professional care, but also of the impact on parents of inadequate staffing. The shortage of midwives is seen as putting an increasing pressure on maternity services.

Accounts of indifferent and sometimes appalling standards of cleanliness from the 1980s onwards are usually attributed to the contracting out of cleaning services and the quick turnaround in bed stays, particularly in city hospitals. Although childbirth is much safer due to technical advances, fears are expressed about future levels of care being at risk.
Part I

4 Long term conditions; patient support groups; mental health

Living with long term illness

‘I feel the NHS has let me down.’

From the beginning, the NHS was better at dealing with acute rather than chronic conditions. In the early days people’s expectations of help for longer term conditions was low. In 1949, the few references suggest that people felt they had to put up with conditions that were not life threatening. After all, they had just gone through a devastating war. In 1942, an MO directive which asked about the impact of the war on people’s health demonstrated a high degree of stoicism, even bravado in not taking medicines, as these comments show.

I take very little medicine. One quarter of a gram of Epsom salts, taken in very small quantities every morning cured my rheumatism for over a year. I missed a morning and the pain came back. During the bombing last year I bought a 100 aspirins and took one every night. I never had an aspirin before or since, steadied my nerves wonderfully ... My mother who was in an area that had been bombed heavily regularly took Sanatogen during the raids but has since given it up. [2850 working class man from Droitwich]

The night before last, I took an aspirin for toothache. I do not recall taking any other medicine since coming to [X] in 1939. If the drug manufacturers lived off me, they would have a thin time. [2841, male doctor from town in Kent]

It was not until the 1990s that diabetes, chronic asthma, heart disease, neurological and mobility problems were systematically addressed by the NHS. The first National Service Framework for people with neurological disorders was produced in 2005.

MO patients and carers in 1997 and 2008 reported the full spectrum of chronic illness, some multiple. For example a retired teacher [P1009 f 68, 2008 ] has spent ten years caring for her father (with diabetes, heart disease) and her mother-in-law (with dementia, hysterectomy, cancer of the larynx). Correspondents wrote about problems in getting a diagnosis. Others struggled to get information about their condition and then had to come to terms with it. Some did write positively about their experiences of specialist help or community support, but there were criticisms of the expertise and attitudes of doctors.

Health issues dominate my life ... When I was finally diagnosed [with M.E.] I felt an enormous relief after so many years of despair and disbelief from other people, but this lasted all of a few minutes. My doctor said, “Yes, I think you’ve got M.E. but no one knows how to treat it or what causes it, so go away, rest and come in for a chat every few months if you want to.” I felt abandoned ... When I visit my GP, I feel very anxious; terrified that one day he’ll refuse to sign my medical certificate. Doctors always seem overworked, harassed and short of time ... On more than one occasion, my GP has greeted me with the words, “Oh good, it’s you, you won’t take long, and I can catch up on my surgery.” He signs the certificate and I leave. I feel the NHS has let me down. [1997 A2801 f 31 York, ex trainee solicitor now unemployed, M.E. for over 8 years]

One of my main criticisms with the system is that often patients are kept in the dark in the hope of promoting a more positive attitude. I often come back from
a consultation unable to really tell my family anything concrete as we are playing this long term waiting game. I personally think that the patient has a right to know and if told can cope better with the facts. I hate this paternalistic approach of we know best and will protect you. [1997 J2799 m 33 Skelton in Cleveland, former supermarket manager; records a year’s treatment for leukemia]

Hospital doctors can be aloof, resentful of questions but also show concern, worry too much. They need a balance between being in control and being domineering, being sympathetic and being patronizing and understanding the patient’s feelings without getting upset and vulnerable themselves ... When one is ill, a good health service matters more than anything else. [1997 A2212 f 41 Watford, author, with severe rheumatoid arthritis]

Our daughter died in June 2007 at the age of 42. She had suffered from Cystic Fibrosis and had been on the lung transplant list for 18 months prior to her death. All her life she experienced the NHS either as an out-patient or in care for regular periods in hospital. She constantly needed various drugs throughout her life and variations in these to stave off the regular infections she experienced. After her death we were able to express our gratitude to the staff and doctors at the CF unit, [X] Hospital, for it was there that our daughter received a standard of care which was beyond the norm in its affection, care and attention for her every need in her last days. [2008 P3209 m 68 Welton East Yorks, artist]

My younger son ... in his 40s is disabled. He has overcome writing problems, first with a typewriter provided by the education services (in the 1980’s) and now with a PC and the internet, and he still draws and paints. State aid has helped him to lead as normal a life as possible – like a long term car lease under the mobility scheme. He has his own housing association house just a mile from us and a responsible executive job with a charity. [2008 P1326 f 70 rural area near Bath, ret civil servant]

I feel, often, when we tell the consultant something, he is interested in it as a symptom because he hasn’t quite come across this symptom before! [2008 A4127 m 45 Nantwich, unemployed, caring for a relative with Parkinson’s disease]

When I moved to Cambridge, I was put on the doctor’s list and was given a thorough check up. It was found I had type 2 diabetes, irregular heart beat and now tinnitus. So my relationship with doctors and staff at my health centre is very good. [2008 N403 f 71 Cambridge, cleaner]

I hate going to my GP as I feel there is a complete lack of joined up services. Each time you go in, they look at you as new and your problem in isolation. If I had done this as an occupational therapist I would have been struck off. My friend who has Graves disease found this out when she was put on medication which was detrimental to another condition that she had, and the GP had not looked beyond the problem he was facing. They get paid huge amounts of money but miss the basics. [2008 J289 f 43 N Wales]

Summary
The difference in expectations of those suffering from long term conditions between the early years of the NHS and more recent times, is shown by more frequent references to their treatment, good and bad. Good communication with doctors and joined up treatment are most valued by patients; and a caring approach and access to good community support is appreciated by their families.
Patient action, self help groups and volunteers

‘I couldn’t have got through these years without them.’

There was a continuous thread throughout the responses in 1997 and 2008 of people being involved with patient action in a number of ways. Some were members of a support group for a particular condition, such as diabetes, or helped to run an organisation like the National Childbirth Trust. Others acted as advocates, for example at a local branch of MIND. Volunteers, usually women, mentioned in passing the work they were doing in hospitals, hospices and agencies such as the Red Cross. There were occasionally descriptions of specific campaigns to deal with local health care complaints. General support was expressed for patients’ rights including, in 1997, for the Patients’ Charter.

Self support activities were often referred to, but only in passing; there were few dramatic passages to quote. For those involved as patients or carers with long term conditions including mental illness, they were clearly important. Support for these organisations was listed by some among their priorities.

You hate support groups right up to the point you actually need one … It was brilliant to have somewhere to go where people understood what you were talking about … [From the original group] We formed our own little support group between ourselves, and I couldn’t have got through these years without them. [2008 A2801 f 42 York, has had M E since 1988; also wrote in 1997]

For the past three years, I have done some voluntary work for a local Mental Health Group which has involved at times membership work, admin. work and general assistance at the Drop In, along with talking with some users about their problems. This is an excellent facility for those with problems but is generally underfunded and heavily reliant on volunteers. Community care on the cheap! [1997 T1285 m 48 London, local government officer unemployed]

‘It’s that personal experience that we want the investigating team to hear’ writes a Staffordshire correspondent who has sent a press cutting describing the success of a patient action group to which he belongs in getting both the local hospital trusts and the Healthcare Commission to discuss their complaints. [2008 B1654 m 76 Staffs, former newspaper manager]

Summary

One correspondent sums up the importance of patient support and advocacy. A retired nurse [2008 M2061], describes herself as ‘patient, carer, family member and volunteer’. She had looked after her husband with renal dialysis at home and went with him to meetings of the Kidney Patient Association. Later she attended meetings of the Tinnitus Association on her own account. As a widow she now works at a local hospice as a volunteer receptionist where she helps to provide care for patients and their relatives. She said: ‘I supply the listening ear or shoulder to cry on’. From her many perspectives, better and sustainable government funding for self help groups so they can help each other is a top priority.
Living with mental illness
‘Sometimes just sometimes I do need help, but there is none for me.’

Ever since the start of the NHS, mental illness has been the Cinderella of medicine. In 1949 mental illness in the family was still something not to be mentioned and it was largely absent from MO accounts. At that time, medication and therapies for mental disease were rudimentary and it is likely physically surviving the war was their main preoccupation. The MO survey of 1942 on the effect of war on their health, showed that people were more likely to talk about their physical health and mental health appeared not to be an acceptable subject to refer to. Typically the remarks were:

My health always was good but its better now. [1206 f aged 37]

The war has had no serious affects on my health. I am thinner, as are most people I know. [2854 f aged 54]

My physical health is rather better on the whole ... I also find the restriction on meat helpful, as I find that it suits me better ... and so far, we have sufficient fish. I also find it beneficial to do without cream, which never suited me but was a normal part of our diet in peacetime and it was easier to eat it than to argue about not wanting it but I miss fresh fruit. [1577 f, works in the bank in Burgess Hill]

Some health workers who corresponded in 1997 did refer to early mental health regimes. While one remembered fondly a self sufficient community in the 1930s, others described the hospitals of the 1960s and 1970s as ‘depressing, remote, forbidding, regimented.’ There were accounts of the detrimental effect that care in the community policies of the 1980s had on patients.

C1883’s husband trained as a mental nurse in the County Asylum in the 1930s. It was a self sufficient community. On a return visit years later: ‘One of the patients turned away with a sigh. “No, it’s not the same” he said “you wouldn’t like it here now”’. She describes her work with mentally handicapped men and how community care failed them when they had to leave the hospital for ‘care in the community’. She asks: ‘What is supposed to happen to them when they get old and ill?’ [1997 C1883 f 73 Stafford, ret nursing assistant]
‘The hunchback [is begging] at the gates, really a dirty alleyway, he used to live in a mental hospital apparently quite happily for many years. A woman is also begging nearby; both were better cared for in hospital.’ The writer sees no progress since she worked as a nursing assistant in Belfast mental hospitals in the 1950s. [1997 A1292 f 64 Croydon, part time teacher, grandmother]

By 1997 and in 2008 the devastating effect of long term mental illness on patients and their families was movingly described in the accounts of some correspondents. Those suffering from recurrent bouts of depression when they were offered different treatments with varying success. Long waits for help and lack of continuity were frequent complaints.

‘It seems a waste of a life’. [1997 C41 f 37 Shetlands, housewife and student of homeopathy; her brother developed schizophrenia at 17]

A woman described how her son-in-law’s mental breakdown was ‘catastrophic’ for his children. [2008 B1180 f 69 S Coast, ret clerk]

I have received excellent treatment over the past 14 years for a depressive illness. I was in hospital four times between 1982 and 1988. Fortunately a continuing course of medication has all but cured me but there has been support when needed from my local Health Centre ... [He has repeat prescriptions for lithium and routine blood tests] How have things changed? From a purely personal view they have got better. Twenty years ago I attended a small Health Centre with a doctor who seemed to care little for people with mental health problems. [He has now moved from a suburban area ‘where perhaps mental health was “not quite the thing”’ to a large council housing estate.] The attitude here is both more sympathetic and at the same time positive, which goes a long way to helping and enables the individual to regain confidence and the ability to become self reliant again. There is no preaching and the attitude that mental illness is purely something one brings on oneself does not exist. [1997 T1285 m 48 London, local government officer unemployed]

A correspondent writing in both 1997 and 2008, described his wife’s treatment for longstanding clinical depression (she also has diabetes and angina). By 1997 she had had ‘contact with a number of psychiatrists who have varied in their effectiveness.’ When a change of drugs produced severe symptoms a psychiatrist made a home visit and prescribed Prozac without explanation. Attempts to get advice by telephone were unsuccessful. ‘She has continued to see her GP and he is genuinely concerned and very helpful. But the specialist part of the service didn’t provide the kind of supportive service that people like my wife particularly need.’ His wife seemed to have had most help from an earlier therapy group which she attended for three years. Not surprisingly, this correspondent put better funding and organisation of psychiatric and mental health services high on his list of priorities.

In 2008, he reported that his wife had had some success with cognitive behaviour therapy (CBT) sessions which were ‘very good and very helpful and lasted long enough to be really worthwhile. But this contrasts with other times when any specialist help was either just not available or because of lack of continuity was not very helpful. The organisation of psychiatric care just doesn’t seem to be clear and the resources for it are not adequate.’ [1997, 2008 B2710 m 78 Newcastle-upon-Tyne, ret clergyman]

When I phone [the hospital] in floods of tears because I can’t cope with her ... they tell me to go and have a cup of tea. My daughter has me and that is all she will ever have, they will never help us. I give up ... sometimes just
sometimes I do need help, but there is none for me. [2008 D156 f 55 SE
England, manages a flower shop; cares for a daughter of 32 with mental health
problems and special needs]

P3213 referred to various experiences members of her family had had with mental
health services. She complained of a three year wait for her son to be treated for
elective mutism. Although the team then ‘spent a lot of time assessing him and you
couldn’t fault them for their efforts,’ she felt that the long wait could have had a
serious impact on her son’s development. Her brother ‘sees psychiatrists rarely and
hardly ever sees the same one twice so he receives no consistent care thus wasting
NHS resources.’

She herself spent time in a psychiatric unit three years ago when suffering from
depression and anxiety. She described the unit as modern and purpose built but
both treatment and environment as inadequate:

‘This is not an environment which is going to do anything to make depressives
feel better,’ said another patient. This correspondent subsequently found group
therapy treatment within 20 miles of her home: ‘The staff were magnificent and
the programme gave me back my life.’ [2008 P3213 f 41 Wales, housewife,
mother, volcanologist]

P1282 had two granddaughters with long term health and education problems
arising from their mental health conditions; one had anorexia and bulimia, the other
had been cutting herself. She wrote despairingly: ‘I suppose the NHS do their best
but help for problems is very limited and continuity seems impossible as staff
change so often.’ [2008 P1282 f 69 Lichfield Staffs, BA Hons, carer for
grandchildren]

Doctors now treat the whole patient not just the particular complaint. There is
more understanding of mental illness and stress, with more help from
community psychiatric nurses. [1997 W2322 m 52 Staffs, deputy head teacher]

I work in mental health and there I can say there has been a huge difference in
only about three years. Basically more money’s been spent on it! But the whole
ethos of how you look after a patient is hugely improved, and it’s good to say
that people who have experienced private care and NHS care can’t fault the
care people receive in my hospital. Privately the main plus seems to be the
quality of the surroundings and the food, but the most important part, the
treatment, seems to be on a par. [2008 A1706 f 62 Shoreham-by-Sea, ward
clerk, artist]

Summary
In recent years people have become readier to talk about mental health problems
which they or members of their families have experienced. A number of
correspondents write about the variable success of treatments they have had;
problems of continuity and availability of psychiatric treatment are particularly
mentioned. Those caring for family members with continuing mental illness take on
a lifetime’s commitment and say they often find it difficult to get consistent
support. Improvements, for example cognitive behavioural therapy (CBT) have
proved useful to some patients and there are reports of better care from GPs and
community psychiatric nurses. It is heartening to hear of the benefits for patients
which can be seen quite quickly when funding is increased, but MO accounts show
that there is still far to go.
Part I

The cyclical history of 60 years of dental services
‘There is no NHS dentist … I do miss my dazzling smile. I look like the wickedy witch.’

Dentistry has been seen as a priority over the 60 years of MO Directives. Relief at being no longer worried about costs in 1949 changed to worries about finding an NHS dentist in 1997 and 2008, when some correspondents reported having to travel considerable distances or give up and pay privately. While changing dentists seemed to be quite easy in 1949, scarcity made this a problem in later periods. In 2008, even when correspondents found an NHS dentist, many thought the charges were prohibitively high. There were good reports of the NHS, particularly where there had been a long relationship with the same dentist or group, but some described poor treatment. Others found standards better with a private dentist, apart from the cost. Orthodontists and hygienists were regularly mentioned, though even when available, waits for appointments were long and costs problematic. In general, fears for the future of a national dental service were prevalent.

Dentistry in 1949
‘I have received nothing but benefit and relief from anxiety.’

Dentistry under the NHS is definitely a benefit … I can well remember desperately saving every penny of my pocket money to pay a series of dentist bills and forfeiting a much needed winter coat to pay for X-rays etc. – after all, health is of the first importance. At least the bugbear of bills has been eliminated. [4004 f 28 secretary. She waits weeks for an appointment where it used to be days but finds the treatment just as good as before, if not better. The dentist offers to insert two teeth.]
The poor man is desperately rushed – but hopes this will subside. [1666 f 51 single housewife Cornwall. Has to book six weeks ahead but will be squeezed in if in pain.]

The dentist said: “Will you let Mr. Bevan pay or do you want to pay yourself?” I said: “I have paid him so he can pay you.” [The dentist said] he was more than satisfied with a very generous scale of payment ... He was as friendly and efficient as ever. [0179 m 35 Home Office school master]

One out and as it looked like a lot of bother to use the scheme I gave him the fee ... I want to see as little of any of 'em as I can! [0154 m 44 electrician]

The state of dentistry in 1997

‘My main concern is that we have no NHS dentist.’

We need more dentists on the NHS ... My dentist went private about a year ago and I cannot find an NHS dentist near my home who will take me on ... It has cost me £136 this month for dental treatment and I go every six months for a check up, which costs me £20 for about 20 minutes. (My husband’s take home pay is about £136 per week). I hope to try to keep my teeth. I cannot afford false ones, and I cannot really afford dental insurance at £11+ a month. [B2066 f 56 Norfolk village, assistant nurse in NHS]

My main concern is that we have no NHS dentist. All the local dentists have gone private and will enroll you in an insurance scheme, but you have to have the work done before they will take you on. I don’t mind the grey hair, the wrinkles, the slowing down process, but I do miss my dazzling smile. I look like the wickedy witch and my grandson says my teeth are yukky. [B1180 f 59 Isle of Wight, information assistant]

I have rotten front teeth, they’re all loose, and they are in terminal decline. [E188 m 60 Telford Salop, various professional jobs, security guard]

The dental practice I had gone to and supported for decades suddenly and without notice ‘went private’ and I felt personally snubbed and politically stubborn. So I turned elsewhere. Still private (they nearly all are) but I moved on principle … Anyway the new one is young, pleasant and thorough, so I’ll stay there. [E1510 m 71 Rugeley Staffs, ret minor civil servant]

[Three sons needed orthodontic treatment; the oldest had had excellent treatment in Glasgow and the youngest more recently had a very good orthodontist in Sheffield, 40 miles away, but for the middle son] ‘The attitude in Lincoln was that it wasn’t bad enough to do anything’ ... My son was just left. We couldn’t afford to pay and we couldn’t afford to travel … In fact this son suffered agonies from his terrible teeth and it is only now and in recent years – he is soon to be 28 – that he is coming to terms with his looks. [A1473 f 54 Lincoln, dinner lady supervisor, former teacher]

Dentistry in 2008

‘Dentistry on the NHS is now a joke.’

I remember at the outset of the NHS there was a stampede for free glasses and dental care, particularly false teeth, items that many at the time could not afford ... In those early days optical, dentistry, chiropody were all catered for, items today we find are difficult to obtain within the service ... The recent collapse of the dentistry services has been another NHS failure in the past decade, with patients being coerced by fortune seeking dentists to take out expensive health insurance cover which incidentally does not cover all treatments, or suffer the threat of being
disowned by dentists who have known the patient for many years. [L1504 m 82 Ottery St Mary Devon, ret administrator]

I am sorry I have to complain though about the whole situation – fiasco – with dentistry. It is appalling that people cannot register with a dentist – and even worse, probably couldn’t afford to have work done even with NHS fees. It is amazing and very frightening that such a situation exists. [B1120 mature lady living in London village, singer, counsellor, writer]

My family and I have been fortunate so far in having a good NHS dentist, but there is always the worry he may leave the service and go private. The shortage of NHS dentists is acute and there are horror stories of people digging out their bad teeth because they cannot find, or afford, a dentist. Something really needs to be done urgently. Two of my grandchildren have very crooked and twisted teeth. They are at present having orthodontic treatment at the local hospital. Although A. was referred when she was 12, the waiting list was so long that she has only just started treatment. She is now nearly sixteen! [P1282 f 69 Lichfield, BA Hons, cares for grandchildren]

Dentistry on the NHS is now a joke. There are hardly any NHS dentists to be found [in Wales]. The first one we did find was useless to the point of wondering about his qualifications – he failed on two occasions to spot a problem with a bridge I have. When I pointed it out he admitted there was a problem but said there was nothing that could be done about it. I couldn’t find another NHS dentist so had to go private and that dentist picked up the problem without prompting on the first visit and fixed it. I am not of course saying that all NHS dentists are incompetent but it is certainly my experience that they are hard to find. We now have accepted that private treatment is a necessary evil and our experience of private dentistry has been excellent. [P3213 f 41 Wales, housewife, mother, volcanologist]

[Changed to a private dental practice about 25 years ago because of the good reputation of the dentist.] I had some political reservations about using a private dentist, and still do, but, unlike using private medical care, I do not feel I am disadvantaging anyone else. I am not ‘jumping the queue’. I would never use private medical insurance because it undermines the whole ethos of the NHS by creating a two-tier system – quicker help for the better-off. [B1475 f 64 Chesterfield, ret auditor]

[After moving to a new area went to a private dentist.] There was no hope here of NHS treatment when we asked around … we were surprised to find it little more expensive than NHS treatment. However there is no hygienist which I miss and the premises are rather basic … The dentist and his assistant constantly exchange gossip when you are in the chair, plus they have a local radio station blaring away, and the receptionist isn’t very friendly either … I’ve bought a battery operated toothbrush which helps make up for the hygienist. [G226 f 67 Fylde coast, ret counsellor, therapist, researcher]

D2585 [has been in the same [NHS] practice for 30 years and has a very good female dentist who asks after the family] … ‘this can make a visit to the dentist less stressful and [more] calming … I am horrified when I read of the treatment some people have experienced at the hands of dentists, some with little qualifications, also the fact that so many dentists do not take NHS patients, and people have to travel long distances to be treated by a good NHS dentist. [D2585 f mid 60’s near Bristol, p/t medical secretary]

My wife and I have attended the same NHS practice for 35 years approximately. Last year our dentist retired and a new, young man took over. Bang up to date,
careful, attentive and it’s as good as it could get for something you dread doing. This is a fair sized practice with 6 dentists, their nurses, 2 hygienists and reception staff. In the last 5-6 years the premises have been tarted up and older gruffer receptionists replaced with more professional folk with a bit of a personality. The lingering anticipation of discomfort and even pain has been eased somewhat. [M3085 m 58 Falkirk Scotland, ret through ill health, now runs the home; ex sales rep, clerk, co-ran a comic shop]

Dentistry, so far as I am concerned, has always been good in my local practice, expensive, though NHS … My dentists have not been English people for many years, coming from India and the Near East, but are well qualified and speak good English and their surgery is within walking distance. I am never afraid to go to the dentist as they give me sufficient but not unnecessary pain relief and there is no unnecessary paperwork … There is not a long wait for appointments, especially in an emergency, such as a broken tooth, and not usually long to wait having arrived at the dentist. [B2605 f 76 Staines Middx ret civil servant]

Dentistry is something I dreaded for years, following a frightening experience in my 20s. Currently I have an excellent dentist who also offers NHS treatment. I was very fortunate in finding him (after my private dentist retired). He is a one man surgery but has arrangements in place for emergencies when he is on holiday. Appointments are efficiently handled and if in pain he will ‘fit you in’ the same day whatever that ends up as! Both my doctor and my dentist are small operations and I do hope it remains that way as they are so efficient and know their patients very well. Friends who use large multi doctor/dentist surgeries tell me they have to wait days, sometimes weeks, for appointments, and feel their relationship with the practitioner is very poor – something that concerns me greatly as I feel it affects the resulting treatment. [B1911 f 66 Watford, ret head teacher]

Summary
In the early years of the NHS people’s dental health steadily improved until the reorganisation of dental services in the 1990s made it increasingly difficult to find an NHS dentist. By 2008 those who could afford it were often forced to go to a private dentist and even those who had an NHS dentist found the cost was high. Privatisation of dentistry had spread through the back door, leaving poorer people with little alternative but to let their teeth rot. Are we coming full circle to the situation before 1948? There were real fears from many MO correspondents for the future of the nation’s dental health.
Part I

6 Care of older people, including dementia

‘With the rising number of elderly citizens, the NHS is going to face its greatest ever challenge.’

In 1949, older people were potentially major beneficiaries of the NHS. Prior to its inception, only people in work were insured and many older people ended up in the workhouse or were untreated. They had also lived through wartime austerity. In 1942, MO issued a directive asking how the war had affected people’s physical health. One correspondent, who was a Medical Officer of Health in Ramsgate reported: ‘I can say that the health of the town shows no measurable deterioration, in spite of our terrible weather problems’. [2841]

Expectations of good health from the 1949 MO correspondents remained undemanding. They did not want to ‘bother the doctor for small things’, and were not used to taking care of their health. Older people were one of the main groups who bought over the counter medicines (analgesics, laxatives, digestives, tonics and vitamins). An MO Bulletin published in 1953, which quoted from a survey of what people had in their medicine boxes in 1949, showed some did not even get this far in caring for themselves.

Yes, we’ve got a medicine box, but it doesn’t have any medicines in it. We’ve had it since the war, the first aid box. It’s got iodine, bandages, a pair of scissors, gauze, a tube of burn-oil, and permanganate of potash. [68 year old manager of a perfumery store]

[Only 1 in 4 had a clinical thermometer.] I don’t believe in keeping one of them. I know someone who does and she’s always popping it in and it puts the scares in you. [50 year old painter’s wife]

It is against this backcloth of low expectation and demand that subsequent responses of the older generation must be assessed.

1997, the NHS at 50

‘We have care by the community not care in the community.’

By 1997, the parlous state of older people’s services was central to thinking on public policy. There had been the introduction of the Community Care Act in 1990 as a response to the increasing numbers of older people and the escalating cost of private residential care. This gave a greater role to the independent sector and reinforced the separate responsibilities of health and social care. Our correspondents were vociferous about older people maintaining independence and having good quality care at the end of their life, including dementia care. They had strong views on what care would be needed in the future and how it should be paid for, a topic we will return to in chapters 9 and 10. Correspondents gave mixed pictures of the care they had experienced themselves or for members of their families. Their narratives and opinions captured contemporary dilemmas about caring for older people.

With the rising number of elderly citizens the NHS is going to face its greatest ever challenge … It’s no good just waiting for the crash and the beginning of that is already happening … Deregulation in this field has created a situation where we have care by the community not care in the community … The profit motive will always drive down levels of care to the patients … On the surface the
places look nice. New carpets and nice shiny reception areas but a lot of the level of care is poor. [He also identifies low wages and untrained staff at care homes.] [J2799 m 33, Saltburn by Sea Cleveland, ret from managing supermarkets when seriously ill and took an OU degree]

This man supports means testing for residential homes because: ‘the old have limited future commitments, the NHS should not be their descendants’ bequeathers.’ [E1510 m 71 Rugely, ret junior civil servant]

What is the point of all these old people sitting around just waiting for death? [B2240 m 75 Chichester, ret pensions advisor]

The age and worthiness of a patient should not be factors. Treatment should be given if it is considered to be of some positive benefit. [B2785, m 50 Cambridge, designer/illustrator]

During my Mother’s last illness in 1986 I found the N.H.S. gave all the necessary help. Our doctor was kind and patient and for the last month the hospital was caring. Earlier we had to wait some months to attend the pain clinic and I only discovered this by accident. [B653 f 65 Cirencester, carer, describes herself as retired daughter of the house]

I feel we should all try as long as possible to look after our elderly people, but I would not expect my daughter to be too lumbered with us … I would not like my daughter to become worn out, she has a job herself (a very good one) and I want her to enjoy her life. I have had a good life myself and am still sloughing on. [A1223 f 71 Newark on Trent, ret clerk in a clinic; she has cancer and cares for her husband who has Parkinson’s disease]

I want to stay in my own home until I die. I don’t want to live with other old folk. I’m not a social person; I enjoy my own company for days on end … More beds, homes for elderly, help at home for elderly patients to free beds. [E 174 f 73 Manchester, ret head infants school]
Yes at 83 and having a heart condition I could do with help in some small things. Bed making takes my breath away. My walking is impaired and just somebody to take me out in my wheelchair would be a treat. Shopping is another necessity, but my daughter takes me about every three weeks and I stock up ... [Her children are working but her church will help] ... I must tell you ... that I have an excellent GP He treats me with respect, will always come up to see me and does not expect me to go to his surgery. He is a gem. Wish more people treated the elderly as he does! [B36, f 84 Rayleigh Essex, ret shorthand typist]

Dementia care, 1997

In recent decades, the specific care of people with dementia has been highlighted by our correspondents. They told detailed stories of what it is like on a day-to-day basis, caring for a loved one whose faculties have deteriorated and their feeling of being alone in a situation which was not being taken into account by the services.

At the start of my taking over my father’s care, medical people were still treating me as an interfering son and talking to him as if he could follow what they were saying and make reliable responses - despite the fact that Dementia was diagnosed. He did not help me by retaining his social graces to the last always appearing affable and trotting out cliche answers ... One of his fantasies was that he had better go to the post office and get his money; something he did over and over again at one stage, testing the patience of the post office staff who all knew him ... as time passed the medical profession came to trust me ... new rules [he is referring to the Patients’ Charter] meant that every doctor/nurse/social services person we met asked for the same details ... how he could manage, how he was being looked after ... no one ever consulted or trusted anyone else to have asked the same questions ... Once my father was hospitalised I could only feel guilty at first and visit as much as possible taking him out on those last sunny months of his life in 1995. He was dressed in whatever clothes were available but quite well enough and because of the incontinence, how else could the laundry cope ... I would like to have seen a greater emphasis on finding out more about the patient’s past likes ... I did prepare my suggestions in writing but it was overtaken by fighting staff cuts going on under my very nose. When ultimately they admitted they had reduced numbers below proper strength for the ward, for all sorts of reasons and of course without telling anyone, and then my father’s death, I was too worn out to continue with it. I could see the great difficulties staffing wards which are truly the cinderellas of the NHS [elderly demented] and the pressure on staff to be kind and patient all the time, in situations when I had become exasperated myself, looking after one. [D 944 m 57 Colchester, ret assistant bank manager]

My late husband ... had Multi-Infarct Dementia for many years. I became aware of there being something wrong many years before anyone medically took any notice of me, and consequently both my own health and our relationship suffered, because the GP at the time was either ignorant of the symptoms or not too interested in my concern. [Her own health deteriorated and he was investigated and diagnosed and after a period at home eventually admitted to a nursing home.] During his time at home, I paid for various items, by then not supplied by the NHS and for the various respite care homes ... had I been better informed, I would have had more years of financial help than I did. [Z 53 f ret fashion artist, volunteer in a hospice]

I know cases where a husband or wife is suffering from Alzheimer’s Disease ... and a partner is expected to look after them at home for much of the time – which is extremely difficult when they themselves are elderly. I suppose it is the penalty we’re paying for an extended life expectation. There is obviously a limit to the available funds for health and care in the community and these are never
going to be sufficient to meet everyone’s expectations. I think elderly people may receive less than their due but then they probably need far more of what is on offer than any other age group. [G2134 m 78 Cheam Surrey ret civil servant, working in health]

2008, the NHS at 60
‘The care which we inflict upon our elders will become, in history, the scandal of the late 20th and early 21st century.’

The issues related to older people in 2008 were similar to 1997, but the tone had changed. Expectations of higher standards of care in hospitals, residential homes and at home were evident, possibly because of media scandals and the greater impact on families of increasing numbers of people living into old age. Help remained scarce and eligibility for social care was squeezed, causing correspondents to make thoughtful comments about how costs should be met. There were more frequent references to quality of life, and of death, for older people, with a range of viewpoints on the subject of euthanasia. While many reported good quality care being provided with dignity to older people, as many described poor standards of care, where age discrimination and lack of human rights were cited, especially when people had dementia.

In some respects, the patient care [for frail older people] has deteriorated in recent years and no amount of complaining has made any difference to the standards of care given to older people. [She visits hospitals.] Meals and drinks left to go cold on bed tables because the patient can't reach or is unable to feed themselves. We have to send staff up to the hospital at mealtimes to make sure people are fed and have often had to wash and change themselves and men always have to be shaved. This is a hospital with 5 stars ... People frequently come to our care [from hospital] without discharge letters, without their medication, with only some of their medication, or even the wrong medication. [R1321 f 62 Basingstoke, nurse, recently worked (Dec 2007) in a private nursing home as matron]

[The story of GRANDAD, aged 90, who fell.] They were so busy concentrating on his poorly knees that it was 5 days before they noticed his ankle had become puffy and painful. Another X ray revealed he had broken an ankle ... so they had to set it, and now he had a large plaster cast on and could not put any weight on it. Then his next misfortune was to catch a hospital bug, he went down with Nor virus and was immediately transferred to a small room and was barrier nursed ... When he felt reasonably fit again they began to complain that he was occupying a bed that was urgently needed for other patients ... it was decided to put a care package in place, with carers going in 3 times a day ... It was found no carers were available, as they were in very short supply ... So a quick visit to a hospital for knee X ray had led to a 5 week stay in hospital and a period of some weeks’ immobility, involving all the indignities of total care. [L1696 m 90 Wolverhampton, grandchild writing on his behalf]

I was already aware that elderly patients in wheelchairs were left marooned in the corridor [in A and E]. One gentleman asked me if I could get someone to phone his wife, who was coming to collect him ... A confused elderly man in a wheelchair who had fallen in the High Street, and had a cut on his head, did not appear to have anyone looking after him. He was still in A and E when I left the hospital four and a half hours later, and during that time I did not see him being offered anything to eat or drink, although someone had arrived to take him home. [M1395 f 77 Sudbury, retired civil servant, executive, attending hospital for an X-ray, April 2008]
She got progressively weaker and was admitted to hospital, it was a secondary cancer that spread. She was in her mid 80’s and was really too weak for treatment. She was put in the female ward, with other old ladies. No one really told her what was going on. I think the elderly ladies enjoyed being together; they were sociable and caring towards each other. They were funny about the nurses. I think they were all Filipino at that time, and the ladies would say, you really can’t understand them but they are kind. The only way we found out what was going on was my father used his PhD – he introduced himself to the doctor as a Dr and the doctor presumed he was an MD and he explained everything!

[M3055 f 33 London, compliance manager, talking about ‘My grandmother’]
My husband … died last month. He was 97. Our doctor had been unfailingly supportive and encouraging. Never have we been made to feel that L. deserved only second class treatment on account of his age. In the past year, doctors have uncomplainingly made home visits and have varied his medication in attempts to relieve his condition. I must not leave out the district nurses … They have visited and supplied equipment, have made referrals to social services, enabling the OT team (part social services, part NHS) to provide a wide range of aids, even an electric rising chair, which made all the difference to L’s last weeks, making it possible to avoid hospital admission. [He died after an emergency admission to hospital]. The staff were warm and helpful, did not hurry me as I said my last goodbyes, and made everything as easy as they could. The following day, our doctor came to the house to complete the death certificate, when I told him just what had happened, he said firmly, “I believe your husband had died at home and that is what I shall record on the certificate. It’s much nicer.” I was surprised but he was right, it is so much nicer; nicer to put in the local paper, nicer to be able to tell people and to remember myself that, whenever the heart has actually stopped, effectively my husband died at home. So, at present, I am full of admiration and gratitude for the NHS. [P2546 f 82 Hereford, ret social work manager]

Both my parents died in nursing homes. My father was moved from hospital to a nursing home 6 weeks before he died. The nursing home was very expensive, £730 per week, but he died with dignity and the staff were lovely. His room was cosy and warm and the home could do more for him than I could. My mother went unconscious the day before dad died and I had a slipped disc!! So it was a difficult time. My sister-in-law and I went from Mum to Dad each day and we were with my father when he slipped away. The home rang to say that his time was near, we both cried with the Matron and then I said the Lord’s prayer and a general prayer for help and guidance - I couldn’t bring myself to tell mum. I had the rest of the family to tell and I was next of kin.

Two days later Mum recovered consciousness and two of the nursing staff came with me to tell mum (who was eating her 3rd bowl of porridge). I held her hand and told her we had just lost dad and one tear trickled down her cheek. Mum couldn’t speak - she hadn’t spoken for over 4 years, and I asked her not to leave me for a while whilst I got over Dad. Mum lasted 5 months. I’d spent the day with her, sang her favourite hymns and looked back over her busy life. My sister-in-law called, as I left about 5 o’clock, the manageress asked if I wanted to be called through the night. When she died, I was so tired I asked if they would let me know and they rang the next morning to say she had slipped away in the night, very peacefully. (I’m writing this with tears.) [R860 f 60 Stockport, retired lecturer, JP]

I think more effort should be put into providing care at home. When my granddad was dying at home with cancer he was fortunate enough to have a ‘Marie Curie’ nurse and it was thanks to her help medically and emotionally, that my granddad was able to die at home, my grandma by his side. (She died 4 days before her 93rd birthday). [A 3961 f 26 Arnold Nottingham, homemaker]

Dementia care, 2008
Dementia was again highlighted by many people in 2008 and a mixed picture was described.

My aunt with dementia spent her last four weeks in the [X] Hospital due to a chest infection that the nursing home couldn’t care for. The hospital doctors expected my Aunt to die two weeks before she succumbed. It was tragic but my Aunt had always been a fighter and somehow, without medication or food, clung on. The hospital couldn’t have been more kind and attentive and informative,
and were very supportive after she died. Nothing could be faulted. Humphrey Lyttleton died there this year. [A883 m 74 Chelmsford, ret architectural clerk]

Mother died with dementia in a home at 92 … My parents didn’t buy a house until they were in their 50s and it was a real struggle … Had they remained in council housing all their care costs would have been met … You do wonder if their struggle was worth it. [R 1025 f 65 Milton Keynes, former book-keeper]

There does seem to be an unwritten rule that every NHS ward has to have a mad woman on it! There was one on my mother’s ward 3 years ago too! In my case it was a frail, elderly lady who was a ‘bed blocker’. She’d been in for months and they were trying to get her moved out against her will. She wouldn’t allow anyone to cut her toenails which curled up so it took ages for nurse to put on her slippers without hurting her. [C2053 f 53 Norfolk, librarian]

I cannot say how strongly I believe that the care which we inflict upon our elders will become, in history, the scandal of the late 20th and early 21st century. My patients’ rights are constantly abused by the system, which seems to imagine that sections of The Mental Health Act are unnecessary when one is elderly … There is no occupational therapy for my patients, who deteriorate rapidly after admission. There is no physiotherapy budget. Pain is constant for many … It is difficult to get medical staff to take this seriously enough and when analgesia is prescribed on a PRN [when needed] basis it is rarely given by anyone but me. I am shocked to my core, even after 7 years working on this ward, that nurses feel so little empathy for a suffering elderly person … The system has become so scared of legal action that it can no longer let people die in peace. Endless intervention seems to be the order of the day and is expensive and seems worthless … patients who may have to die several times over, due to nurses who are scared to make their own secretive evaluation of the situation and will not call a crash team out … I have known a profoundly demented woman of 102 to be resuscitated, with resultant broken ribs, lack of subsequent pain relief, bed rest, subsequent pressure sores and a gruesome death from pneumonia to follow. [N 3588 f 47 Scotland, psychiatric nurse, working on a psycho-geriatric ward]

Summary
Many older people were well supported in their older years and through the process of dying. However, there were numerous examples of lack of consideration for the particular needs of older people in both 1997 and 2008. Accident and emergency care and dementia care stood out. Correspondents’ replies in 2008 were noticeably more critical of service standards, implying that the public’s expectations are rapidly increasing. The greater numbers of older people in the population are well represented among MO responses in the 1997 and 2008 directives. They show that recently retired people have very different attitudes to the pre war group about the care needed by older people.
Part II

Mass observers’ opinions on contemporary ethical and political NHS debates

7 Ethical dilemmas in health care

‘We are fortunate so much research is going on.’

In 1949, people’s basic health needs were paramount in directive responses. By 1997 the ethical issues on the rationing of health care, caused by limitations of health care funding for new and expensive treatments, the increase in assisted conception, the paucity of organs being donated and problems around clinical trials were all in the news. In 2008, ethical debates also included the rapid developments in research on genetics and stem cells. Correspondents were asked about their views on these ethical issues in both 1997 and 2008, and whether their views had changed.

Medical research

Most correspondents were in favour of research with appropriate safeguards. They particularly mentioned the potential application of stem cell research for serious conditions, such as Parkinson’s and Alzheimer’s disease. Over a third of 2008 correspondents had written in 1997; of those who mentioned research, most said their views had not changed, suggesting some fundamentally held opinions. The creation of embryos for research purposes proved to be a controversial subject, whilst funding for research scientists elicited some strong support. There were arguments for and against assisted conception and assisted death, with thoughtful contributions on the complex issues involved. A number of people made reference to being a blood donor and many believed that organ donation should be automatic with an opt-out available. However not everyone agreed – and a case below illustrates that the process of actually donating an organ can be difficult. Here is a range of responses from 2008.

*I have always had fairly strong views on this (not changed over last 10 years). I approve of stem cell research for dreadful diseases like Motor Neurone disease, Parkinson’s, Alzheimer’s etc. On organ donation, I carry a donor card as do other members of my family.* [P1009 f 68 Evesham, ret teacher]
Organ donation and transplants

‘I always feel I should carry a donor card but I don’t.’
Transplants and in particular renal transplants appear in people’s descriptions of their health experiences; waiting for a transplant or refusing one in favour of a younger person are movingly described. Correspondents in 2008 also give their views on organ donation and once again, as with all ethical issues there is ambivalence, but with a strong trend towards supporting an opt-out system.

I always feel I should carry a donor card but I don’t. I know if I was asked if an organ could be used from a loved one of mine, I would be very reluctant … I would struggle with the idea of their body being hacked about. [R1025 f 65 Milton Keynes, housewife, formerly book keeper]

My husband and I both wished his eyes to be used for cornea donation … I received a [30 minute] phone call, on the evening of my husband’s death, from a tissue donation official, asking lengthy questions about my husband’s health, and even where his parents were born! [P2546 f 82 Hereford, ret social work manager]

My brother lost his kidneys to cancer 3 years ago. We are waiting 2 more years before they will allow a transplant, then my sister, my older brother and I will be tested to see if we can be a donor. I can hardly wait … he is only allowed to drink a very little liquid each day and is not allowed chocolate etc. We were in a café and he looked at all the drinks on sale and said “One day, I will come in here and say I will have that and that and that.” I said, I wanted to be there with him when he does. [D156 f 55 SE England, florist manager]

[Was told she would need dialysis in 1996 and] ‘fortunately got a transplant after just 11 months of dialysis – there are so many people who never get the chance of a transplant, so I have been incredibly lucky’. [F4125 f 42 N. Ireland, p/t clerical assistant to school nurses]

What’s wrong with presumed consent? With an easy comprehensible get-out clause for those who find it unacceptable for whatever reason? … no pressure. Most of us are just too lazy to trouble to obtain a donor card … The process … should be standardised. Some understanding of … the bereavement process is essential when dealing with relatives of the dead or dying. [N 1592 f 76 Hebden Bridge, counsellor, ret landlady]

Fertility issues: the need for a debate

‘I believe we can and should help them to have children’ versus ‘we should not play God’.
There was a tremendous range of opinions expressed in the answers to questions about fertility treatment in both 1997 and 2008. Abortion was also the subject of strong opinions for and against, even though there was no specific question in either directive.
In 1997 respondents were asked to consider the ethical issues around creating new life in the context of the rationing of care and what the NHS could afford. Responses were fairly evenly balanced between those who were against fertility treatment altogether, and those who supported it in principle, though sometimes with restrictions. A minority rejected fertility treatment outright on religious grounds or because it was just too expensive. Others thought there were greater priorities, such as the care of older people, or that more needed to be known about the health implications of the procedures. Correspondents in favour of NHS treatment supported part payment by the prospective parents or limitations on the number of implants at a time or of treatments per couple. There were thoughtful contributions from people in 1997 who felt it was not a clear cut issue. ‘Another complicated area, with no blacks and whites, only greys!’ [B2258 f 60 Norfolk, ret teacher].

If I cannot conceive a baby in the normal way, I shall be sad but will accept that as the way it is meant to be … The first world is using up too many resources so people shouldn’t go to great lengths [to conceive]. [B2638 f 35 Manchester, learning resource officer]

Producing life artificially could I suppose lead to some bizarre and ominous results but probably no more bizarre or ominous than those produced now by sexual intercourse. [G2134 m 78 Cheam Surrey, ret civil servant]

I know people who are childless and who are desperate for a baby. Their lives have been severely affected by infertility and I believe we can and should help them to have children.’ [A 2801 f 31 York, trainee solicitor unemployed through illness]

This correspondent’s response in 2008 is somewhat different; she now thinks that it is ‘not an absolute right’ to have children and while the post-code lottery is a disgrace, she believes that several chances on the NHS cannot be justified.

By 2008 developments in fertility treatment as in many areas of research, were receiving increased prominence in the media. Respondents were asked whether their views had changed in the last ten years about the ethics of assisted conception. Although only a few directly stated that their view had changed or remained the same, opinions for and against fertility treatment remained evenly split. Reasons given for opposing it included religious grounds: ‘We should not play God’ [M2061], its inappropriate use ‘in a grossly overpopulated world’ [B2240] and because infertility ‘is not an illness’ [C2053].

Support for fertility treatment included some resounding statements in favour of the associated research: ‘We are fortunate that so much research is going on’ [C1878] and: ‘those that object seem to deliberately misunderstand the aims [behind the research]’ [B2605]. As in 1997 some of those in favour of treatment thought that limits should be imposed on the numbers of attempts or of successful implants. Among the many interesting contributions were thoughts about the ethical aspects of the subject and a description of the procedure for sperm donation

Having a child is a privilege, not a right, and unfortunately for some people, it’s just not meant to be.’ [G3963 f 35 Wales, housewife/mother, formerly construction tax specialist]

I love Robert Winston but IVF is meddling too far. In life we can’t have in every case what we want. In nature if a woman is infertile it is nature’s way of saying “You shouldn’t become pregnant” … Nature knows best.’ [L1002 f 61 Staffs, ret shop worker]
As a mother, I strongly agree with IVF and egg donation and have considered donating my own eggs. The costs for such procedures are expensive and, though it would be fantastic to say that every person should be entitled to it free, it just isn’t feasible. I think this is an area a lot of people don’t understand or have misconceptions about. [A3961 f 26 Arnold Nottingham, home maker]

It’s easy to be philosophically dogmatic until you have some emotional involvement. [Z2276 f 61 Twickenham, p/t admin for national charity]

The abortion debate – sympathy for the pro-choice position

Since 1968 and the beginnings of legalized abortion, I have had very mixed views about it. I have no problem with abortion in the early stages, say in the first 12 weeks or so; but like so many others I am never sure when to draw the line. [2008 B1475 f 64 Chesterfield, ret auditor]

Abortion as a subject was raised by some of the MO correspondents in both 1997 and 2008, even though they had not been asked to address it. Among the range of views they presented, there was a preponderance of pro-choice positions but also a sympathy for the complexity of the subject. Interestingly those who were pro choice for abortion were not always in favour of fertility treatments. One passionately pro choice correspondent had herself experienced an abortion many years ago in life threatening conditions, while a younger woman who had also experienced an abortion now discussed the arguments for and against it. Adoption is mentioned by some as a better alternative to abortion. A male correspondent refers to the problems of his students when being seen by an anti abortion GP. And a woman who is against abortion considers how she would feel if her daughter was raped and recognizes that ‘If it concerns yourself it may be a different answer.’ [B2552]

Views of care at the end of life and assisted dying in 1997

‘I feel the use of modern drugs often prolongs life when it has lost its quality.’

All 4 of my grandparents were dead at my age, I am still healthy but the big wish of my life would be that I could ask for or be given by the doctor something to end my life quickly when I felt my time had come. [E174 f 73 Manchester, ret head infants school]

I have no problems with euthanasia. It’s an option that I would want to exercise myself and it’s a reality that exists in hospital now. Doctors do not try endlessly to save a person’s life when they are at a stage where their quality of life would be non existent. [J2799 m 33 Cleveland, medically ret supermarket manager, doing OU degree]

We both dread the thought of becoming living cabbages ... I would not have liked to be responsible for initiating a euthanasia procedure for either of my parents, but I would certainly like a procedure whereby I could say now, while I am still of sound mind, “Let me die in dignity just as soon as I become confused.” My wife and I both understand that we are neither of us to have a stroke for example we should not encourage the medical staff to keep us alive ... I feel strongly that my life is mine to dispose of as and when I will. [B2240 m 76 Chichester, ret pensions advisor]

I do not agree with euthanasia, however on the other hand I feel the use of modern drugs often prolongs life when it has lost its quality. My husband ... had Parkinson’s for 17-18 years, towards the end he was just a cabbage and when the hospital withdrew his drugs he died peacefully, which I feel is as it should be. [B36 f 83 Rayleigh Essex, ret shorthand typist]
Views on assisted dying in 2008

‘Why should those who wish to die be prevented from doing so by some ethical claim?’

In 2008, correspondents still had strong views on assisted death. The majority felt that where there was no quality of life, it should not be prolonged, but that strong safeguards were needed.

The more I thought, the less capable I felt of making a comment on such a loaded issue [assisted dying]. We know doctors help patients in their last stages at a discrete, covert level – exercising individual judgement, based on their individual beliefs, a decision taken very much within the specific case where suffering, serious loss of quality of life, of dignity is very clear, where the prognosis is hopeless. But such decisions arrive as a result of individual assessment and personal philosophy. Should they be formalised, built in, acknowledged within institutions, department, between colleagues? Unless circumstances were extreme and clear I would not wish to have to make such a decision for a loved one, or probably for myself ... Again we are probably in the hands of the post code lottery. There should be guidelines, universal within our service. [N1592 f Hebden Bridge, ret landlady, counsellor]

They certainly helped my mother-in-law with carefully monitored drugs, and she slipped peacefully away ... You have to have 2 doctors’ signatures on the death certificate and you see for yourself that your loved one will not get better, at the time ... I don’t agree there should be a policy such as assisted death such as in Holland, but if anyone is in so much pain etc, they should be helped so they don’t lose their dignity, certainly not having to go to court and plead for assistance. [I1610 f 64 Duckington, ret nursery nurse]

I am completely in favour of euthanasia. My ‘living will’ was to alert my doctors to the fact I do not want to be kept alive if I lose my mental faculty. Why should those who wish to die be prevented from doing so by some ethical claim? If one kept a sick animal in the same appalling condition you would be arrested for cruelty. [B1442 m 84 Staines, ret aircraft engineer]

Summary

There was a wide spectrum of views, often strongly held, reflecting increasing public interest in the ethical implications of advances in medicine. The implication of correspondents’ range of views is that more public debate is needed on assisted dying, an opt-out scheme for organ donation and on the limits for terminating pregnancies. People want to see an end to the NHS post-code lottery in general, and in particular, around policies and payment for IVF treatments.
Part II

8 Health information, the internet and confidentiality

‘We still need humans.’

In 1997, when MO correspondents were asked to prioritise their sources of health advice and information, doctors came first, then dentists and frequently pharmacists. There was a robust self reliance on finding health information too; one person writes simply, ‘myself’ while others mention family and friends. Different forms of the media are relied upon by some, even including the television series, Peak Practice. Others are ‘deeply suspicious’ of media information[ B2552]. A retired civil servant recalled having been issued with medical dictionaries by ‘the ministry (DHSS)’ where he worked [G2134].

The internet

As a source of health information for our correspondents, using the the internet was limited in 1997. It was welcomed by some correspondents but treated cautiously by others or regarded with outright hostility. Although many older people neither wished to nor had access to the internet, a minority were forward looking about its future use. GPs who used computer information in consultations were on the whole described with approval.

As a pharmacist respected by many local customers, many came to see me as the first line of enquiry about an ailment because my advice was valued and they could see me for free at once without an appointment. Some were referred to their GP while others went away happy – their fears had been unfounded. [M1544 m 63 Bolton, ret pharmacist]

People will not have to rely on 20 year old books in the local library. [J2187 m 42 Etchingham East Sussex, civil servant, very much in favour of IT]
I don’t yet trust what I see on the screen – I feel someone is manipulating my mind. [C2654 f 55 Sutton Coldfield, p/t time tutor, prefers books to IT]

I do not think computers lend a sympathetic ear to illness. [C2078 f 52 Farnham Surrey, carer, ex nurse]

IT is to be used more for diagnosis and treatment and in training doctors but we still need humans. [W2803 m 27 Liverpool, contract engineer]

The doctor has information at his fingertips and it also churns out prescriptions. A great benefit. [B1771 f 61 Mitcham Surrey, ex secretary]

However, people differentiated between information about disease being available on the internet and the use of the internet for transmitting personal health data, which was not well received, with many people being concerned about confidentiality.

My GP presses a few keys and my medical history is soon revealed on the screen. [But she wonders] Bank computers have been invaded so why not surgery and hospital records? [B89 f 66 Leighton Buzzard, ret audio typist]

Future interactive computers may eliminate bureaucracy. [W2529 m 72 Morecambe, ret manager of day centre]

I am horrified by the thought of health information by computer. [C1939 f 62 Ipswich, ret radio programme monitor]

By 2008, there was a general reliance on the internet by younger correspondents though many older people still avoided it. Overall, there was still a strong belief in face to face contact with doctors.

A few years ago I developed a minor ear infection and, without my asking, the GP wrote the name for me so that I could look it up on the internet. But it is essential that we are careful not to believe in what we read too much. There is no substitute for real professional expertise and reading all the information can make you a chronic hypochondriac. [C2053 f 53 Norfolk, librarian]

I think everything in relation to the internet is great. It is a useful tool which can supplement the information held by health professionals. It is not a supplement for the actual professional themselves. I do not use the internet for health information as I am rarely sick and would rather visit the Doctor. [L3298 f 50 Liverpool, local government officer]

I don’t have access to the internet. I’m too old to learn. I can’t even manage a mobile phone. [B1442 m 84 Staines Middx, ret engineer/RAF]

I have used the internet to find out health information e.g. to see if shingles was contagious but I don’t think you can beat going to see an expert to get that peace of mind. [B3635 f 33 Colchester, primary school teacher]

Confidentiality and the use of personal data

However, in 2008, confidentiality had become a major concern. During the preceding decade, the use of electronic communication by health organisations as well as individuals had made a quantum leap. Parliamentary legislation on the sharing of information and data protection did not prevent scandals about the use of personal data for profit or inappropriate sharing of records, creating similar worries for people about their medical records. The need for adequate regulation of access to electronic health information was often trenchantly expressed.
Some correspondents thought patients had a right to see their medical records, but attitudes to sharing information between doctors and patients ranged from positive, to equivocal to negative.

I personally don’t care who has access to my medical records as I have led a particularly bland and blameless life. No abortions, sexual diseases, attempted suicides or drug taking. Anyway, the way things are going with everybody on the internet, no one will be able to have secrets any more. As I am a Luddite, I don’t use the internet. [B1898 f 76 Hailsham East Sussex, ex claims assessor]

Patients have these days the rights to see notes written about them. It seems amazing to me now that this is such a recent innovation. [B1475 f 54 Chesterfield, ret Executive Officer Audit Commission]

Patient information should not necessarily be shared between doctor and patient. Sometimes a doctor has to judge a patient’s ability to deal with a situation. My husband doesn’t want to be told everything. (I do!) [L2281 f 75 St Albans, ret teacher]

Medical records should be electronically stored and available in the NHS. If business managers can keep people’s records in line with the Data Protection Act; the government should be able to. The internet is such an advancement for humans we should use it wherever possible. I do use the internet to sort things out. It is really good for background about conditions and travel. It is very good. [M3055 f 33 London, advancement compliance manager]

I would never wish to use the internet or other electronic means to share any medical problems with anybody, including the medical profession. Such things I believe are a matter of person-to-person contact even if I have to make appointments and wait my turn in the queue. I should feel too much that my details and personal information could be intercepted in a similar way that credit-card-fraud takes place regularly via the internet. No doubt in the future there may be a fail-safe means of using the internet for medical advice etc but this will not, I believe, be secure enough for me in my life time. [P3209 m 68 Welton East Yorks, artist]

I have to be concerned about the use of computer systems to store [health] information. Governments have a poor record in having IT systems developed and it must be realised that these systems are provided by private companies. If the MOD can’t get it right, we can’t expect health authorities to do so. I don’t use the internet for health advice. [M3085 m 58 Falkirk Scotland, ret through ill health]

The track record of the authorities losing our records, or selling them to a third party, makes me worry about a ‘big brother’ future. [B323 m 72 Norton Disney, ret sales manager]

The concerns I have about the development of electronic systems and the privacy of patients’ records and data protection are not restricted to the NHS. [A3434 f 43 Winchester, ret from stock market to look after young son]

I do have concerns about access to medical records and the development of electronic systems of information-sharing. Even with the data protection act, it is obvious that personal information is available to any commercial or investigative organizations who want it and regulatory bodies seem very weak and ineffective about breaches of the code. [H2447 f 73 Oxford, acupuncturist]
One phrase guaranteed to send a shiver down most people’s spines is ‘a new computer system for the NHS’ … It is the sort of thing politicians promise and the rest of us lose sleep over as our private details disappear in a puff of smoke, if we’re lucky, and if we’re not, into the wrong hands. [C3167 m 37 Stoke-on-Trent, warehouseman]

I would rather share information than keep everything in compartments so that one service has no idea what’s happened to me in another. The sooner the whole thing is on a decent single system, the better. Any breaches of information security should be dealt with through existing laws on theft. Same goes for the Internet. As a professional tool it must be invaluable. I’m sure the “worried well” turning up with a sheaf of Web pages is a real annoyance to GPs and others – but at least it shows people are interested, and it’s only a modern version of the old medical dictionary on the sideboard. [03259 f 43 Selkirk, self-employed health and social care planner]

Summary
Sharing of information for clinical reasons between health professionals is acceptable to patients. However people worry about the many blunders in other areas that have taken place with loss of data on the internet. They want their personal agreement sought for their data to be used in research or to be shared outside the health service, and to be assured of the confidentiality of their health data. While many correspondents now see the internet as a regular source of health information, many older people do not like the internet, and most people continue to regard face-to-face contact with a health professional as their best source of information.
Part II

9

Priorities, preventative health and
the public health debate

‘It seems everyone has rights but not all have responsibilities.’

Priorities

There was a great deal of consistency about what correspondents’ priorities for NHS spending should be in 1997 and 2008. Where people had listed their priorities in both 1997 and 2008, GPs and hospitals came top. In 1997, this was followed in two out of three cases by dentists. Many wanted to see less spent on managers or ‘bureaucracy’. Future care for older people was a concern for people who were themselves elderly or had older relatives. More nurses, better out of hours services and improved access to A and E were mentioned. People argued that investment in para-medical services, such as physiotherapy, would both benefit the sufferer and the NHS purse.

If I was in charge of the health service, then I would say that money should be re-channelled into medical care and out of bureaucracy which has grown up’. [1997 B1386 f 57 Oswestry Salop, school secretary]

My concerns now are access to emergency care, an affordable dentist and optician, and good care in later years. [1997 S2083 m 66 Kingston Lewes, semi-ret shop accounts manager]

Growing old and infirm is not a choice in the last years of one’s life! This is where the help should be provided – not for unhealthy life styles. [2008 B786 f 73 Barnstaple, secretary/PA]

I would spend more on care at home rather than in hospital wherever possible – care at home is cheaper and more people prefer it. Revival of the district nurse scheme would be a good investment rather than using poorly paid and inefficient carers to save money. [2008 P1009 f 68 Evesham, ret teacher]

I think more money should be spent on high quality staff, on the midwifery departments where there is a huge need for more midwives (after all they are the experts in obstetrics, not the doctors who only see the patients who are having problems), more and better care at home, and in the case of home visits by care staff, a much higher grade of carer ... I know that millions of pounds could be saved by the NHS and also millions of lost ‘man-hours’ regained from speedier manipulative treatment of bad backs, frozen shoulders and sciatica etc, instead of the constant visits to the GPs who merely prescribe Ibuprofen, painkillers and adding patients’ names to a 6 month long waiting list to see a physiotherapist. [2008 H2447 f 73 Oxford, acupuncturist]

The public health debate

‘Preventative treatment would save the NHS a great deal of cash.’

The extent to which it is the job of the NHS to keep people healthy, rather than treat disease, generated a great volume of contradictory views from our respondents. In 1997, the directive asked whether NHS money should be used to support leisure centres and GP prescriptions for swimming lessons. These were being promoted by policy-makers at that time and indeed free swimming for older people has become a widespread reality. The responses provide a case study illustrating the complexity of shifting NHS resources to preventative programmes.
While health education and advice, including exercise and swimming did receive support, it tended to be with reservations: ‘fine in an ideal situation’ or ‘acceptable for the incapacitated or the poor and disadvantaged’. Those who did support swimming on prescription thought that this might be cheaper than pills. A more forceful contribution pointed out that ‘The NHS tinkers round the edges of public health policy’ and should be tackling the tobacco lobby amongst other preventative measures.

For others, free swimming was ‘taking it too far’ or ‘impractical’. There were a number of responses from those who felt that people should be responsible for their own health through exercise and generally healthy living, and that ‘people appreciated more what they pay for’. The issue brought out occasional references to ‘Health Fascists’ and the ‘nanny state’.

_Fitness is not the job of the NHS. There is plenty of health advice available._ [C2717 m 31 Nottingham, mechanical engineer]

_No to swimming lessons on the NHS ... people have the right to ‘abuse the body’ with smoke, drink etc._ [B2552 f 65 Grimsby, ret midwife]

_Health is one’s own responsibility where known risks can be avoided._ [B2675 f 55 Croydon Surrey, p/t admin]

_I would have liked swimming lessons and more time talking to my doctor to avoid early onset angina._ [Z583 f 73 Derby, ex office worker/typist, student of history in retirement]

_Swimming lessons on the NHS - a nice idea! [also] more preventative medicine and alternative therapies, exercises on prescription ... Feeling good is a major step in getting better._ [B2638 f 35 Manchester, learning resource officer]

**Views on rights and responsibilities in 2008**

‘All have rights to health care. We can’t enforce responsible lifestyles even when it costs everyone more.’

Concerns about funding and preventative care are inextricably linked to views on what should be available through the NHS as of right and how much responsibility people should have for their own health. The 2008 directive specifically asked who should have rights to health care. Responses varied from wanting full cover for those who had ‘paid their stamp’, to only in emergencies, or not at all, for incomers of various kinds. Others thought that free health care should be completely universal for whoever needed it, as a mark of a civilized society.

_Free health care should be for people who have National Insurance all their working life. NHS funds are reduced by the costs of non-working people on benefit and immigrants._ [M2061 f 77 Nottingham, ret SRN; she writes as a patient, a carer, a family member and as a voluntary worker]

_Those who have paid into the NHS should get treatment but people from abroad (non EU) should have their own insurance._ [C108 f 73 suburbs, grandmother]

_A free at the point of use, universal NHS is one of the signs of a civilised state._ [M3085 m 58 Falkirk Scotland, early ret sales rep and ran comic shop]

_A more general question about people’s responsibilities and lifestyle choices with particular reference to drugs, alcohol, smoking and diet, generated equivocal and sometimes inconsistent responses from people who were tolerant of a particular_
lifestyle choice because of their personal experience, but intolerant of others. The topic was clearly highly emotive. Some thought that patients who abuse their health should pay towards resultant medical treatment or go to the end of the queue. Others believed that penalising people with unhealthy lifestyles could prejudice any activity with an element of risk such as sport asking ‘where would it end?’ On balance, a liberal view of the general right of access to health care prevailed.

I believe every person has the right to decent health care but some people do take advantage of the system, people for example who have made poor lifestyle choices (drug users, smokers). Often these are the people who need most help, or develop serious problems … I smoked from the age of 14 to 24 but quit because of my health. I didn’t want to die young. The same goes for diet. I am on a low income, yet I ensure my children get a healthy diet. If people can afford to smoke, they can afford to pay for the health they need. There are plenty of free support groups (New Leaf) and often N.R.T. is free to certain people … I discussed the issue of whether people who do smoke/make bad life style choices should get treatment with my mum. At 52, she has smoked for over 35 years and is a chronic asthmatic. She felt strongly that yes, people like her should get NHS treatment, as she has worked continuously since her adolescence and in her words ‘paid her stamp’. [A3961 f 26 Arnold Nottingham, home maker]

Everyone has the right to receive health care to start with, but if they deliberately abuse the system (e.g. by abusing staff or ignoring advice) then they should not get infinite chances to do it again. Send serial offenders to punishment practices with the rudest receptionists, the worst waiting rooms and the longest waiting times … Prevention is a legitimate Government activity but there’s a limit to what prevention can do. I don’t believe anyone who smokes needs more information about risks – they know, and smoke anyway. Ultimately it depends on the balance of risks. [O3259 f 43 Selkirk, self-employed health and social care planner]

It seems everyone has rights but not all have responsibilities. [He worries about] binge drinkers etc using up valuable resources and depriving others with healthier life styles. [M3085 m 58 Falkirk Scotland, early ret rep and ran comic shop]

Trying to cure people of addiction is a very small step at the wrong end of the problem. Easily available drugs and drug pushers not being punished are the problem … A neighbour still smokes and has had five years of heart treatment; this is unfair to non smokers waiting for treatment. [B2605 f 76 Staines Middlesex, ret civil servant]

People are beginning to realise they should look after their own health but the doctor can’t force anything for example about obesity. If you drink like a fish and smoke eighty a day you can’t expect to be treated like someone else. Some illnesses are self inflicted. If you are size 32 or worse isn’t it your own fault? There should be more fun things on the NHS to encourage fitness and healthy eating. [C1191 f 53 Northern Ireland, carer]

Smokers and the obese should contribute to their treatment. [C2053 f 54 Attleborough Norfolk, librarian, now office worker]

I think we all as individuals have a responsibility to look after ourselves. Somehow though to actively withhold care from smokers or drinkers etc is too prescriptive. But perhaps there is some happy mid ground where patients forfeit certain types of care if they are not prepared to help themselves … some sort of
‘three strikes and you are out’ system. [A3434 f 43 Winchester, ret stock market to care for her son]

Smokers etc should get free health care otherwise where would you draw the line and who would pay the extra staff to make the decisions? [D156 f 55 S E England, manageress of flower shop]

There will be problems if there is discrimination about life style choices and health. [M1201 f 45 Chester le Street, housewife]

Summary
Correspondents had little doubt that priority should be given to front-line medical and associated services, more resources for older people, with definitely less bureaucracy. Views on lifestyles that affected health and the extent to which the state should take responsibility and intervene were more contentious and divided. This suggests that these public health issues require more coverage and debate. Similarly, the responses about eligibility for NHS care were mixed. Though the prevalent view was that anyone living in the UK who was ill should get care, this was frequently tempered by restrictions. A number of people felt strongly that the NHS should only be for those who had ‘paid their stamp’. This indicates that, in a climate of financial stringency, there needs to be greater clarity about who is eligible for NHS care.
Part II

10 The NHS of the future and how to pay for it

‘We must preserve the NHS, it is unique and invaluable.’

Over 60 years, expectations about the role of the NHS by the public, politicians, professionals and patients have changed radically. In the 1940s, the NHS was dealing with a pent up demand for basic health care from people, many of whom were already ill or debilitated, but who had been unable to afford it. Most members of the public were enthusiastic about the NHS and just grateful that the worry of paying for doctors’ and dentists’ bills had been removed. In 1949, although there were thoughtful comments about the costs nationally of the new system, correspondents were not then thinking about how it might develop in the future.

\[Now I pay weekly just the one contribution, which covers us all for everything. The removal of the dreaded doctors bills during a long illness of one of the family is a godsend & I’m perfectly willing to pay up weekly & never use the services, in fact, I’m wholeheartedly in favour of the health scheme. [4307 m married one baby]\]

[The government should] impress on the rank and file of the country the fact that they are not getting something for nothing. [4625 m ex navy]

Shifts in views in 1997
‘The chassis (of the NHS) is beginning to wear out.’

Fifty years after its inauguration in 1997, the enthusiasm for the NHS was maintained. But by this time there were worries about the lack of investment in an ever expanding service.

\[I and millions of others had great hopes and excitement for that time. Most of these hopes were justified in the event. [E1510 m 71 Staffs, ret civil servant]\]

\[In those days I think everyone was enthusiastic about the very new NHS. [B2240 m 78 Chichester West Sussex, ret senior manager]\]

\[After 1948] The Common Man could enjoy what others had previously bought. [P2034 m 69, Newark Notts, ret music master]\]

Nevertheless, MO correspondents expressed the hope that a new government would inject more funds into an overburdened system. They had real fears, echoed later in 2008, that the NHS might have to change in fundamental ways. Despite some questions about the future affordability and the bureaucracy and management of the NHS, or whether universal cover could be afforded, people continued to overwhelmingly support the NHS as an institution. This was expressed in strong, sometimes passionate terms. The issues that came up again and again were: willingness to pay for the NHS through taxation; worries about the impact of the privatisation of health care; the inequities of differential payment systems for health and social care; the acceptance that ‘something needed to be done’ about sustainability. There was no discernible difference in younger and older people in support for an NHS paid for by taxation.

\[We thought the NHS was there for everyone in 1945 and after 50 years we are in a sorry state with money the priority … Care should not be rationed by the ability\]
to pay … I would pay more – one p on income tax would be fairest. Everyone paid one p per week for the Red Cross in the war. We could use some Lottery money too. [C1878 f 76 Newton Abbot Devon, housewife, voluntary counsellor]

I was born just three months too early to be an NHS baby but apart from those three months, I have lived my lifetime, so far, under the auspices of Aneurin Bevan’s great social creation. And what a creation it is – the NHS. [T1285 m 48 London, local government officer unemployed]

I think the NHS is still a wonderful organisation even if the cracks caused by lack of funding are beginning to show. [B2638 f 35 Manchester, learning resource officer]

I should be very SAD and ASHAMED if there were not to be an NHS … It has been one of the very civilised events of what is quite an uncivilised century. To abandon it would be a poor reflection on man’s inhumanity to man. [W1893 m 72 Felixstowe Suffolk, ret chemist in food industry]

[The NHS] may look different in the future but so long as the poorest of us is able to call upon it in time of need as most of us can at present, I will gladly pay more income tax from now until doomsday! [T2459 m 81 Birkenhead, ret railway clerk]

Will people have to pay for what they use in future – like they now do in dentistry? [B2605 f 67 Staines Middlesex, ret civil servant]

It would be a tragedy if elderly people like me see a return to a completely private system. OK for some, but there will be losers all right, as there were under the old panel system – and it is not too difficult to guess who they are likely to be. [R1418 m 75 Derby, ret decorator]

I think the best years of the NHS are over and I suspect it will be everyone for themselves with long waits for the poor. The NHS should be publicly funded but there are many non contributors (not necessarily their fault) and some freeloaders. Contributors will resent the increased pressure but all will lose if no solution is found. [C2053 f 43 Norwich, unemployed librarian]

Will the NHS in the future cover only basic care for people on income support? A sort of PDSA for humans? I am in favour of tax rises and would pay more – I was against earlier tax cuts. I don’t want more charges (e.g prescriptions) when I am ill. That is just when I don’t want to be landed with a massive bill. [B1665 f 63 London, ret hospital clerk]

The NHS will always exist because people won’t pay privately. [C1713 f 48 Preston Lancashire, receptionist]

I fear for the future of the NHS … The time when need takes precedence over the ability to pay, is passing rapidly I fear. [B2785 m 51 Cambridge, self employed designer/illustrator]

[The NHS] is the heart of society and must be maintained. [B1440 m 78 Bognor Regis, ret linotype operator]

I will need the NHS I know for the rest of my natural. I only hope it’s around to provide the level of care I have had to date. [J2799 m 33 Skelton in Cleveland, on invalidity benefit with life threatening illness, ex supermarket manager]

‘Long live a free NHS.’ [A883 m 63 Chelmsford, architectural clerk]
What people were saying in 2008

By 2008 it was clear to many correspondents that despite a decade of heavy investment, the NHS of the future would not be able to meet all demands. People were starting to reflect on previously unthinkable ways to inject more money into the system, such as hotel charges in hospital or some non essential services being outsourced. However, creeping privatisation and a two-tier NHS were also major concerns for many correspondents. Memories were long and the original purpose of the NHS – free care for all – was still being invoked. Correspondents’ comments reflected the current debates on NHS and social care priorities and funding. They also demonstrated that the public is well aware of the political and financial realities of the modern NHS. This is just a sample of their views and ideas:

I remember the time before the NHS and the stampede for glasses and false teeth when it began – things many could not afford before ... I am sure Bevan would not like what has happened to it now and would have used his vitriolic language to sort most of the current problems out ... I think the NHS will become a private organisation funded by the large insurance companies. [L1504 m 82 Ottery St Mary Devon, ret admin]

Health care needs will always exceed funds. Too much money was put into the NHS too quickly leading to massive waste and endless reorganisation and tinkering with the structures. Private finance and profit in the NHS is a dangerous illusion. I think money would be better spent on education ... I would like to see a single organisation, independent of government and responsible for all health care, monitored by an independent body and funded by government. We need universal free provision of health care funded by fairer taxation with the rich being taxed more. [B2710 m 78 Newcastle upon Tyne, ret clergyman]

I applaud the fact that (on the whole) health care is still free at the point of contact and hope that it remains so. However I feel that if people wish to make a voluntary contribution to the costs this should be made easy but it is important that no pressure be brought to bear on anyone to contribute. It certainly should not be means tested. I would be happy to pay hospital board; those on benefit and children should not pay. [M388 f 77 Norfolk, ret lecturer married to GP]

Problems with the cost of the NHS might mean compulsory insurance with a safety net. [B3323 m 72 Norton Disney, ret sales manager]

The state i.e. the taxpayer should pay for the NHS. But there needs to be a readjustment of the budget so that our taxes pay for more health care and less bureaucracy. I would welcome the opt-out from the NHS of private health care payers – they should perhaps pay h/c insurance out of pre tax income and then be excluded from the NHS? [A3434 f 43 Winchester, ret from stockbroking to look after her son]

I and my husband paid N I all our working lives so we expect free NHS care but accept that costs have escalated. Where do you draw the line between health and social care? Older people need both. The pension does not often cope with paying for social care so the need for medical care increases - at a cost to the NHS. [M2061 f 77 Nottingham, ret SRN]

I firmly believe that funding for health and social care, particularly for the elderly, should come under the umbrella of NHS funding and not be off-loaded to local authorities. [It should come] out of one pot ... Unfortunately this would probably mean increased NI contributions but people cannot expect the services they demand if they are not willing to pay for them. Many people happily pay contributions to private health care so I see no reason why they should object to
increased contributions for better health care. [R1321 f 62 Basingstoke, nurse
and in 2007 matron of a private nursing home]

I remain wary of more private care delivered for the NHS because it is quite
objectionable for the NHS which funds GP and nurse training receives little or no
contribution from the private sector to then profit over and above this. However
if it alleviates serious waiting lists and reduces a backlog giving the NHS time to
deal with operational issues then we just have to bite the bullet. [L3298 f 50
Liverpool, local government officer]

I see very little in the media about anything positive to do with the NHS, yet I’ve
had mostly positive experiences with the NHS. [G3963 f 35 Old Colwyn Wales,
housewife, formerly construction tax specialist]

I expect you might get quite a lot of moaning as a result of this directive, which
goes to show how quickly we get used to things we once couldn’t have dreamt
of. To think that anyone in this country can get access to the best medical care
in the world is pretty remarkable. I’m not sure I can talk about a relationship
with the NHS as though it’s a brand like Tesco. It’s more a case of coming
across individual health care practitioners, who all get paid by the NHS: but
they’re so different, and so variable, that you can’t really think of them as
representatives of a single organisation. It really doesn’t feel like that. There are
good and bad doctors, and hospitals, just like there are good and bad schools.
[H4234 m 37 Leeds, cultural sector consultant]

The National Health Service must always be protected and guarded from political
interference which might endanger its future. If the NHS was privatised it would
be a betrayal of everything that the best efforts of social progress has achieved
in 60 years. It is the envy of ‘progressive’ societies such as the United States
and European countries. I would happily contribute more of my money in tax in
the belief that I could assist this wonderful service than waste it on armaments.
[P3209 m 68 Welton, artist]

I have had very good experiences of the NHS and know what it was like before.
Others take it for granted and expect miracles. For me the NHS is a miracle in
itself ... The NHS should be a joint undertaking between potential patient and
state. [W1893 m 84 Felixstowe, ret production manager]

Summary
The future of the NHS is clearly a highly charged issue for our respondents. We
have only been able to show a tiny proportion of the sentiments, the experiences
and the opinions that people have voiced but we have reflected their range and
variety. It is evident that they are actively thinking about ways in which the service
can be improved and how the NHS can continue to be funded. Their comments
illustrate the extent to which ordinary members of the public do understand the
complexities of the NHS and are capable of being engaged in the consultations
about its future.
Part III
Authors’ summaries and messages

In the previous chapters, we have given precedence to the narratives of MO correspondents, enabling them to tell their personal stories of the NHS. Our role has been to select texts that also illustrate the broader history of the NHS through the range of their experiences and opinions. In this chapter, we are highlighting the predominant issues and themes that have emerged from this rich material. We are also adding messages of our own, based on our extensive experience with patients and health practitioners, which we think provide pointers to the debates on the future of the NHS. We would like to acknowledge the many stories about dedicated NHS care told by writers over the 60 years of correspondence to the MO Project. However, for this chapter, we have concentrated on the problems and the need for improvements raised by MO correspondents.

Part I: Mass observers’ experiences of 60 years of the NHS

Hospitals

Lack of cleanliness
Acquiring an infection like MRSA in hospital was one of MO correspondents’ greatest fears. They repeatedly described appalling examples of dirty hospitals and careless cleaning. Contracting out of the cleaning services was viewed as a main cause.

Our view: Basic hygiene should be an intrinsic part of everyone’s activity in hospitals, not an add on in just some people’s jobs. Nurses should resume a key role in the management and maintenance of good practice and standards. Consideration needs to be given to in-house cleaning for wards.

Communication
As patients, MO correspondents asked for respect when being addressed and clear and honest communication about their health condition. They wanted clarity about the status and roles of different staff and who to complain to.

Our view: Levels of ward management and staff roles, including that of hospital matrons, need to be distinctive and clearly discernible to patients. Complaints should be constructively encouraged and dealt with in a timely fashion.

Nursing care
Poor and inadequate nursing care, especially for frail or elderly patients, was reported more often in the 2008 responses (in comparison with 1997). This observation tallies with other research from the Patients Association and the DH Dignity Project.

Our view: If urgent attention is not given to restoring the previously good image of nursing, it is likely to inflict serious damage on the profession’s reputation and diminish trust in nurses diminished.

Accident and Emergency
Many confusing and frightening experiences were reported in A and E during long waits for attention.

Our view: Many people, especially those who were older, appeared to be at A and E only because of the lack of availability of other more appropriate services, such as good out of hours general practice. Extended GP opening hours and more GP units for minor conditions attached to A and E departments could appropriately reduce long waits for patients and relieve pressure on hospital staff.
Hospital to home
Lack of suitable care packages and coordination between hospital and community services continued to cause ‘bed blocking’ and inadequate follow-up care at home. **Our view:** Despite a longstanding focus on hospital discharge, it is clear that the processes still require attention. More resources are needed for imaginative home care packages, and community re-ablement, including the use of community hospitals.

Dignity in hospital
The lack of privacy in overcrowded wards meant that intimate conversations, for example about diagnosis, were overheard. Patients complained bitterly about mixed sex wards, and in particular, mixed gender toilets and bathrooms. **Our view:** Good clinical outcomes are being undermined by lack of attention to other aspects of quality care particularly privacy, especially when delicate personal issues are being discussed. Intimate care in a mixed sex situation, whether in a ward, bathroom or toilet, is undignified and is unacceptable. This has been recognised for decades and clearly needs resolution.

Out patients clinics
Patients reported long waits, overcrowded waiting rooms and a failure of continuity of clinical staff, which affected the care of people with long term conditions (see below). **Our view:** MO correspondents have described examples of good experiences, showing what can be achieved by simple management and culture changes that are patient-centred, such as timely appointment systems. These examples are capable of being replicated.

Hospital food
There was a wide variation in the quality of hospital food and some older people were not being helped to eat. **Our view:** Besides being a basic quality marker, lack of attention to food is a resource issue. Better standards of nutrition would improve patients’ recovery times and could lead to fewer days in hospital.

Hospital parking
People complained frequently about the difficulty and expense of hospital parking. **Our view:** The government review of hospital parking in England is to be welcomed if it leads to more sensible arrangements that take into account greater use of day care, and the importance of visitors in patients’ recovery processes.

Private care
With improved waiting times for surgery, by 2008 fewer correspondents were using private care. They were generally pleased with its quality but aftercare was poor and they reported that costs and restrictions were increasing. Most people did not use private care. **Our view:** Higher costs and stricter criteria are likely to make private care harder to afford in the future, particularly for older people. This will result in higher costs for the NHS.

General practice
**Appointments systems**
On the whole, patients were happy with their GP and very much appreciated seeing their own doctor. Major problems persisted with general practice telephone appointment systems and with some reception staff. Long waits to see named GPs resulted in less continuity and a variable quality of care, particularly for older people and patients with long term conditions. **Our view:** At present there is a perverse incentive with the DH target for GPs to see...
patients within 48 hours of making an appointment. Patients who are really ill cannot see their GP immediately because appointments are taken by people with minor ailments or non urgent problems, who might be able to wait longer. There is a knock-on affect on A and E (see above) and out of hours services (see below). Sensible GP appointment systems would have a positive impact across a range of NHS services as well as improve patient satisfaction.

Computers in the surgery
The highly valued one-to-one contact with GPs could be impaired by insensitive use of computers for diagnosis and treatments, which made patients feel that the attention was on the computer and they were not being listened to. Our view: GPs need to explain clearly to patients the purpose of the computer in checking diagnosis or drug options, so that patients feel involved in the consultation and appreciate the benefits of IT.

Specialist nurses
Specialist nurses’ expertise was valued by patients but was not mentioned often. Our view: The implication of few references to community or specialist nurses implies that they are not universally available, another example of the unevenness of provision. Their roles require more promotion and greater visibility, especially for people with long term conditions.

Out of hours GP service
Criticism of access to out of hours care, its quality and continuity with daytime GP services, was virtually universal across the country. The persisting dearth of evening and weekend surgery hours meant people had no choice but to use the OOH GP service. Long distances to centralised OOH services caused transport problems for older people and young families. NHS Direct was infrequently mentioned, with varying perceptions of its effectiveness. Our view: The widespread and serious criticism of the OOH service by correspondents indicates that urgent action needs to be taken about its appropriateness, effectiveness and safety.

Maternity services
As with general hospitals, a number of maternity units were described as unacceptably dirty. Short stays in hospital when giving birth have resulted in insufficient support for mothers pre and post delivery. Parents identified a serious shortage of midwives. Our view: With the rise in birth rates and the demand for home births, it is clear that many more midwives and health visitors will need to be trained, and those already trained, encouraged to remain or return to work.

Dentistry
Widespread shortages of NHS dentists were described, with fears that there will be long term effects on people’s teeth. The shortage of a range of dental services on the NHS, including dental hygienists and orthodontics, meant that MO correspondents were being forced to pay privately or have no service at all. Our view: If the right to an accessible and affordable dental service is to be genuinely available, then the government must provide incentives for dentists to join or remain in the NHS service. The range of services needs appraisal. For children, reinstating the school dental service could reverse the decline in poorer children’s dental health.

Long term conditions
Increased expectations of positive and consistent medical help for long term conditions were not always being met. MO correspondents described the benefits they received from joined up and integrated services.
Our view: Doctors and nurses with specialist skills are needed to provide a continuum of care and expertise for people of all ages who suffer debilitating conditions.

Patient support groups, advocacy and volunteers
Correspondents were enthusiastic about patient support groups, when they had access to them. Patient advocates and volunteers provided valuable services, often with little or insufficient funding.

Our view: The centrality of patients to all NHS policy is not reflected in funding for organisations that run patient support groups, advocacy and volunteers. Increased funding would enable the time and energy of those who give their services to be better deployed to the benefit of patients and carers, appropriately saving the expensive time of health professionals, who should also have more knowledge and better links with local and national patient support groups. This would enable patients to manage some aspects of their illness themselves.

Mental health
MO correspondents reported some improvements in mental health services in recent years. They were asking for better coordination of services and more information about the range of treatments available, for example, for depression. Carers described a sense of isolation.

Our view: Without improved funding, including support for carers, mental health is likely to remain a Cinderella service.

Care for older people, including those with dementia
Older MO correspondents identified more and better coordinated care, in the home and in the community, as a main priority for funding for older people. They wanted a unified service across health and social care and clarification on funding anomalies. Carers, often themselves elderly, vividly described their marginalisation when supporting family members, including those with dementia. While there were examples of excellent care, poor standards were frequently described, in both general and specialist services.

Our view: Older people are already the greatest users of NHS services, and this will increase as more people survive into old age with multiple health problems, including dementia. Our research indicates that better training standards are required for care workers in state and private homes and hospitals. The government’s proposed national social care service is welcome, though at present it does not adequately address the needs of carers. This could be a lost chance. The announcement that a person has been appointed to lead the dementia strategy also provides opportunities to redress inadequate care standards.
PART II: Mass Observers’ opinions on contemporary ethical and political NHS debates.

Health information
Younger people were using the internet to find out about health issues but many older people did not have access to a computer. Concerns about confidentiality of personal data have grown. MO correspondents generally were worried about the computerisation of their medical records without adequate regulation. Most accepted that their health data could be appropriately shared between health professionals, but wanted their specific consent to be sought.

Our view: Greater public debate on the sharing of personal data on the internet is essential if people’s legitimate concerns are to be addressed and a public backlash avoided.

Research and ethics
There was general support for developments in research such as stem cells and genetics, though with regulatory safeguards. A minority of MO correspondents had religious or moral objections. People graphically described the personal tragedies associated with waiting for transplants because of the shortage of donors. A majority of MO correspondents wanted an opt-out scheme for those not wishing to donate their organs, in place of the current opt-in system.

Our view: MO correspondents’ views indicate that the time has come for government to be more robust in promoting a debate on an opt-out scheme for organ donation. The possibility of a pilot opt-out scheme in Wales is welcome and could provide a template for a UK system.

Fertility treatments and abortion
MO correspondents’ discussions ranged widely on how many, or even whether any, fertility treatments should be paid for by the NHS, but there was widespread support for an end to the present post-code lottery. The current legislation on time limits for abortion procedures was also raised.

Our View: The number of considered responses on both these subjects indicate that people need more information on the arguments for and against different treatment plans and protocols and are willing to engage in a debate.

Death and dying
MO correspondents, except for those with explicit religious beliefs, generally supported a new legislative framework to allow assisted death, including safeguards to avoid exploitation and abuse.

Our view: More information is necessary for the public about what a new legislative framework might look like, and reassurance that people will not be forced into premature death when they do not want it. Training for health professionals would be required on issues such as sensitive communication with patients, family and friends, and the acceptance of Living Wills.

Priorities, preventative health and the public health debate
Most people wanted more front-line staff and less bureaucracy. Older and younger people alike wanted care for older people to be further up the list of priorities for resources. The question of rights of access to health care raised strong views for and against the policy of universal coverage for all sections of the population, including recent incomers. Taking responsibility for staying healthy was strongly debated as a public health issue. There were divided opinions about the NHS subsidising healthy activities and to what extent people with addictions and lifestyle problems should be helped at public expense.

Our view: As pressure on NHS resources grows, it is likely that these arguments will accelerate. The strength and diversity of correspondents’ views indicate that the public needs more information and greater involvement in discussing the role of the
NHS in preventative health, and how much NHS energy and money should be invested in making the population healthier.

The future NHS and how to pay for it
The majority of MO correspondents, irrespective of age, supported a tax based system free at the point of use. Some were prepared to pay higher taxes, sometimes as a designated NHS tax. They did not want an insurance based, privatised or ‘Americanised’ system. A two-tier safety net approach was not acceptable, but there were suggestions that people might pay for some non health services such as hospital board, or that access to less vital services could be limited – though people were unwilling to say what these might be. Fairness in the distribution of and access to health services and removal of the post-code lottery were regarded as fundamental tenets of the NHS.

Conclusion
We believe that the testimonies of the MO correspondents show that the Mass Observation Project is a relevant and valid source of research material which can illuminate both the history and the future of the NHS from the patient’s point of view.

While MO correspondents are not a statistical sample, they are a cross section of UK society. They reflect the range of views and the mood of the general population. This suggests that the public are able, and wish to be fully engaged in debates about the NHS.

Most contemporary MO correspondents are realistic about the future. They know that changes will be needed if funding is to match technical developments and increased expectations. They appreciate that the NHS is one of the most complex institutions in UK society and that perfection will never be achieved. Only a few are pessimistic enough to think the NHS as they know it will not survive. For the majority, the NHS is an intrinsic part of their lives. It has been there from birth to death, during periods of pain and stress. It is a life saver and cannot be allowed to fail. We leave the last words to an MO correspondent:

‘The NHS may not be the “envy of the world” any more, but for all its faults it is still far better than any of the alternatives on offer.’ [C3167 m Stoke on Trent, a warehouse operator]
Appendix
Mass Observation Directives on the NHS
1949, 1997 and 2008

MO Directive April 1949

a) Describe in as much detail as possible your dealings with all health services (e.g. your doctor, dentist, optician etc.) since the inception of the new scheme.
b) Do you think that the new scheme has benefited or hampered you in any way?
c) How does the relationship between you and your doctor now compare with what it was before the scheme started?

Spring Directive 1997

You and the NHS
Next year we shall celebrate fifty years of the NHS which began on 5 July 1948. Some of you may remember the high hopes of the new Welfare State at that time and the fears of those who opposed it; others might have memories of what health care was like before the NHS existed. But for many of you the National Health Service is all you have known.

We should very much like to hear from you about your own experiences of health care whether recent or in the past. This may have been as a patient yourself or as the carer for someone else (no real names or locations please). Please tell us about your good and your bad experiences.

We hope the questions below will prompt a response from you but as always, feel free to write in your own way if that suits you better.

How important are health issues to you?
If they are important, is this because you or someone close to you:
- has had a particular need for health services in the past?
- has a continuing need for health care for mental or physical illness or disability?
- works in health or a connected field?
- works in the voluntary health sector (for example a self help group)
- has a general or political interest in local and/or national services?

Most recent experience
Please describe the most recent experience you have had using health services for yourself or someone you look after. The service might have been provided by the NHS or privately and have been carried out by a doctor, nurse, dentist, physiotherapist or other health professional, or an alternative/complementary health practitioner; in a hospital, clinic, health centre or at home.

How have things changed?
Compare your recent experience with how you remember it 10, 20 or even 50 years ago. How do you think your own experiences compare with those of people you know or with the national picture? In what ways have health services got better and/or worse in your experience?
Relations between patients and professionals
Do you think that the relationship between patients and health professionals has changed? What do you think of the word “patient”? Do you prefer the word “consumer”? What rights do we have as health care users?

Your experience of healthcare in other countries - if any
How did it compare with this country? Please say whether this was on holiday or whether you were living in the other country at the time. What is your opinion about what we spend on health compared with other countries?

Crises and problems in the delivery of health services
We all know that there have been many in recent years. Reasons given include the advances in medical knowledge which mean that more can be done, people having higher expectations (they feel that access to good health services is their right), the survival of more people into old age or with disability and lack of good management or sufficient funds. What do you think?

The rationing of care, and decisions about ending life and about creating new life
These, and other, ethical issues have been in the news recently. What do you think? Have any of them affected you personally, or someone close to you?

Caring for an elderly or disabled relative/friend
Many of you wrote about this in an earlier directive, but if you are able to comment in relation to the health services in this directive reply, we would be grateful. Do you need such care yourself? Are there things - even very small things - which would make your life easier? Not all of them are necessarily expensive; some might not cost anything at all; others might be expensive or might mean changes to the way such care is organised.

Getting health advice and information
Where do you find it? Can you list the ones that are most important to you in their order of importance - some ideas are given below but add new ones if you think of them.
- General practitioner (GP) or someone in your local surgery (nurse, receptionist)
- District nurse or health visitor
- Chiropodist, dentist, physiotherapist or some other health professional
- Consultant or specialist
- Self help group or voluntary organisation (advice line, leaflets)
- Magazine, newspaper, agony aunt
- Radio programme or phone in, television programme
- Medical reference books, specialist literature

Information technology
Do you think this could be a useful to you as a means of being better informed about health? Do you already use it in this way? For example, getting information from the internet, from a teletext system, a medical database, interactive computer programmes or videos, or in some other way?

Complementary and alternative therapies
Have you used any of these services in recent years? How satisfactory has the treatment been? Do you think you will use them more in future?

Private health services or any other non-NHS form of treatment?
Have you used these? Please describe your experience as fully as you can.

Keeping fit and healthy
Do you think it is the job of a National Health Service to keep you healthy as well
as caring for you when you are ill? Nationally or locally would you like to see NHS money contributing to the costs of leisure centres? What would you think of a GP prescribing swimming sessions on the NHS? How do you get information about keeping or becoming fit?

What do you and your family (or those you care for) most need now in terms of health services?
Please can you name about three services or aspects of health which are most important to you at present (or will be in the next few years) listed in order of priority.

If you were in charge of the NHS what would your priorities be?
Now? For the next five years? In the longer term? Things are changing so fast that health services may look very different in the future - do you think there will be an NHS?

And finally, how do you think health services should be paid for?
Would you be prepared to pay more yourself, and if so, how?

MO Directive 2008
You and the NHS in 2008

How have you been treated by the NHS in the last decade?
In 1997, we sent out a directive on the National Health Service as it was celebrating its 50th anniversary. This year, as the NHS enters its 60th year, we would like to ask you to describe what your experiences of health and social care have been over the past decade so we can look at what has changed. If you do not use the NHS we are still interested in your views on private care or on care you have received abroad.

As explained in the covering letter, this directive has been designed by two people who are not only interested in gathering your stories for future generations through the Archive, but are also planning to present your views (summarised in reports with extracts) on the past, present and future of health care to policymakers. Policy makers have access to copious statistics, but are very rarely given the chance to read the words of people who use the services.

NB Please start your reply by saying whether you write as a patient, carer, family member or someone who works in health and social care - you may fit several categories.

Your own experiences of health care since 1997
What improvements and/or deterioration have you experienced? (for example: GP services, out of hours services, hospital services, waits for referral and appointments, physiotherapy and in particular dentistry.) What was your relationship with staff like? Did you feel safe and treated with dignity?

Do you have any experience of private health care or care abroad which you can compare with care received in the NHS?

Please describe any specific health and social care experience from the list below that apply to you and your family: as patients, carers or health professionals
• Childbirth, child or adolescent health
• Long term conditions - for example asthma, diabetes, heart disease, cancer, multiple sclerosis, mental illness, physical and/or learning disabilities
• Older age including dementia, dying and death
• Self help and support from self help groups

Your views on the future of health and social care and the NHS

The costs
How do you think health and social care should be paid for?

Health care priorities
As resources are limited, what would be your priorities? You might want to consider expensive new drugs; further reductions in waiting times; more care at home rather than hospital; more private services delivered in the NHS; or something else?

Research and ethics
Have your views changed over the last 10 years about research and ethics - about, for example, genetics, stem cell research, organ donation, clinical trials, assisted conception, assisted dying?

Rights and health care
Who should have rights to health care?

Our own responsibilities
What are patients’ responsibilities for lifestyle choices (for example, drugs, alcohol, smoking, diet?) Should patients or government pay for self help, preventative services, and medical intervention?

Health information
Do you have concerns about access to information for patients? Should there be sharing of information and records between professionals and patients?

Do you have concerns about the development of electronic systems and the privacy of patients’ records and data protection?

What do you think about healthcare professionals using the internet to share details, diagnose illnesses and obtain information? Do you use the internet yourself for health information, diagnosis and treatment?
Notes and useful texts

Introduction

Statistics on use of health services by populations can be found at the Office for National Statistics, UK health Statistics, No 3, 2008 Edition, Palgrave Macmillan. See also Age Concern, ‘Fit as a Fiddle’ programme for key facts and statistics on older people in 2008: www.ageconcern.org.uk

For more information on the Mass Observation Project, motives and the way correspondents write, and representativeness of the MO panel, and relevant reports, see:

MO Bulletin, New Series 48, National Health December 1952/February 1953, University of Sussex Library
Statistics on MO responses and activities and other directives can be found at the MO project at the University of Sussex.

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For a full history of the NHS, see:
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Other useful texts:
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DH (July 2000) The NHS Plan: a plan for investment, a plan for reform, Stationary Office, Cm 4818-1
Care Quality Commission (May 2009) Survey on cleanliness
The Patients Association( August 2009) Patients... not numbers, People... not statistics, www.patients-association.org.uk
The Patients Association (November 2006) Infection control, is it only skin deep?
Andrew Burnham, Health Secretary, Speech to Labour Party Conference, September 2009
How should we address our patients? Dr. Roger Charlton The GP, 20 March 2009, p49
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See also, reports from The Prime Minister’s Commission on: The Future of Nursing and Midwifery in England, 2009
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DH (15 December 2009) Delivering same-sex accommodation progress report: the story so far, reference 297533

Chapter 2 General Practice
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MO Directive, January 1942, What effects, if any, do you think the war is having on your physical health and that of the people you meet?’
Mass Observation Directive (1942) Effect of the war on the quantity and types of medicine.
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DH (2009) Your experience counts. Patient experience survey. The DH GP Practice Survey is undertaken by Mori
National Patient Safety Agency (April 2009) Take control of hand hygiene, handhygiene@npsa.nhs.uk
DH (2008) High Quality Care for All, DH, Cm 7432, 79, Whitehall, London SW1A 2NS. See also the DH website on personal Medical Services and Quality and Outcomes Framework

Chapter 3 Maternity Services
DH (April 2007) Maternity matters:choice, access and continuity of care in a safe service, product number 278867
See also reports from DH on children and maternity at www.dh.gov.uk
Special edition on maternity services HSJ 23 April 2009

Chapter 4 Long term conditions; patient support groups; mental health
In 2005, DH work on LTC’s identified no targets but 11 quality improvements. See DH website on Long Term Conditions, www.dh.org.uk
DH (5 January 2008) Supporting People with Long Term Conditions: an NHS and Social Care model to support local innovation and integration, Cmd 270415
DH ( 30 January 2006) Your Health, Your Care Your say
DH Patients’ Charter (1991)
See also: Joseph Rowntree publications, www.jfr.org.uk
DH (7 December 2009) New Horizons: working together for better mental health
DH Constitution (Patients’ Rights) www.dh.gov.uk/en/healthcare/NHS Consultation Continues

Chapter 5 Dental services
National Survey on the state of childrens’ teeth, The Argus (Brighton) 21 October 2009 (one in 5 have poor teeth, many do not have own toothbrush)

Chapter 6 Older People, including dementia
DH (1990) The NHS and Community Care Act, Chapter 19
HMG (14 July 2009) Building Britain’s Future, Care, Support and Independence, Shaping the Future of Care Together, Cm 7673
See DH End of Life Care Programme: www.endoflifecareforadults.nhs.uk and Kings Fund: www.kingsfund.org.uk
More information on the quality of older peoples services can be found at the Care Quality Commission: www.cqc.org.uk

7 Ethical issues
‘Euthanasia ‘ Clive Seale Centre for health sciences, London Queen Mary’s University Journal of palliative medicine, March 2005
Crown Prosecution Service (September 2009) Policy on Prosecuting Assisted Suicide, Keir Sturman QC, DPP
See NHS Choices website for a number of reports on research and ethics, including, ‘Donation: ethics and worries’, January 2010, http://www.nhs.uk/livewell/donation/pages/ethics
Roy J Thomas, ‘Wales opts to save transplant patients, Guardian Tuesday 22 December 2009, www.guardian.co.uk

8 Information technology and confidentiality
DH Your health information, confidentiality and the care records service: Answers to your questions, www.nhscarerecords.nhs.uk
DH (8 September 2009) Information Charter

9 Public health, priorities and rights and responsibilities
See DH Public Health and Choices websites, including reports from national support teams: Let’s Get Moving - Physical activity Care Pathway and Coalition for Better Health

10 Funding and the future of the NHS
Audit Commission (12 November 2009) More or Less, Are productivity and efficiency improving the NHS? and ‘is the treatment working?’ www.audit-commission.gov.uk
Acknowledgements

We should like to thank the following for the use of pictures.

Front cover: 5th July 1948. England. Welsh Labour politician Aneurin Bevan with a group of nurses on the day that the National Health Service came into being. (Getty)

Frontispiece Cover of the 1949 National Health Act

Opposite p i Staff Nurses. The RAMC Muniment Collection in the care of the Wellcome Library, London

p vi Claybury Asylum, Woodford. Wellcome Library, London

p 1

p 6 Hospital, minor procedure. Anthea Sieveking

p 11 Doctors or medical students listening to their heartbeats. Wellcome Library, London

p 14 NHS Picture Library

P 17 (L) WWII poster. Wellcome Library, London

P 17 (C) Care of newborn baby. Anthea Sieveking

p 17 (R) NHS picture Library


p 31 (L) Frances McCabe

P 31 (C&R) NHS Picture Library

p 33 NHS Picture Library

p 36 Elderly Llady, nursing home. Anthea Sieveking

p 39 (R) NHS Picture Library

p 44 NHS Picture Library

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