

IMPROVING OUR HEALTH SERVICE

**A PATIENTS'/CARERS'
MANIFESTO FOR IMPROVING HEALTH CARE**

PRODUCED BY

THE PATIENTS' COUNCIL

Contact:- Paul Mainwaring, The Patients' Council, Atrium House, 574 Manchester Rd., Bury, BL9 9SW. E.Mail paul@patientscouncil.org.uk www.patientscouncil.org.uk

CONTENTS:-

TOPIC

INTRODUCTION

SECTION A

PATIENTS VOICE

- a) ELECTION OF NHS BOARDS
- b) COMPLAINTS PANEL
- c) PATIENT CONSULTATION FORUM
- d) N.I.C.E.
- e) NHS PILOTS
- f) NHS SCRUTINY BODY

SECTION B

PREVENTION

- a) AWARENESS
- b) FLUORIDATION
- c) PHYSICAL FITNESS
- d) VISITING
- e) OBESITY
- f) EDUCATION
- g) SOCIAL AWARENESS
- h) STAFF FACILITIES

SECTION C

STAFFING

- a) FRONT LINE STAFFING
- b) STAFF RECRUITMENT
- c) MANAGEMENT RECRUITMENT
- d) MANAGEMENT METHODS

SECTION D

HEALTH CARE

- a) SINGLE HEALTH CARE AUTHORITIES
- b) STANDARDISATION OF HEALTH CARE
- c) USE OF AUTHORISED DRUGS
- d) DENTAL SERVICES
- e) OUT-OF-HOURS SERVICE
- f) APPOINTMENTS
- g) DENTAL APPOINTMENTS
- g) LOCAL SERVICES
- h) DISCRIMINATION
- i) PERSONAL AND NURSING CARE
- j) GREEN PAPER ON CARING
- j) DRUG PRESCRIPTION
- k) SWITCH PRESCRIPTIONS
- l) BASIC MEDICAL RESOURCES
- m) DRUG CLINICS
- n) SINGLE ROOM ACCOMMODATION

- o) HOSPITAL "DAY ROOMS"
- p) SEGREGATED SMOKING FACILITIES

SECTION E
SOCIAL CARE

- a) CAR PARKING
- b) TRANSPORT PROVISION
- c) PROVISION OF NURSING HOMES
- d) ELDER ABUSE
- e) STAFF TRAINING
- f) HUMAN RIGHTS
- g) SHELTERED HOUSING

SECTION F
BENEFITS/FINANCE

- a) LONG TERM BENEFIT RATES
- b) ANNUAL UPDATING
- c) WINTER FUEL
- d) OVER 80's ADDITION
- e) CARING
- f) HOSPICE FUNDING
- g) PERSONAL CARE ALLOWANCE

SECTION G
ALTERNATIVE THERAPY

INTRODUCTION

This Manifesto has been produced by the Patients' Council of North East Manchester - an 18,000 strong organisation which gives ordinary people a real voice in health service planning.

We cover an area which includes Bury, Rochdale, Oldham and North Manchester and have worked in partnership with the area's Healthy Futures reconfiguration programme to engage and consult the local community about their health needs and aspirations.

All our committee members have long term medical conditions. This means they have vast experience of what works – and doesn't work – in NHS provision. But our Manifesto goes much further than the patient voice. We believe that major changes in the way services are delivered are the only way to create an NHS fit for the 21st century.

This Manifesto is an extension of our local work and calls for some radical reforms in national policy; the way the NHS is organised and run and how it delivers services to properly meet needs. We hope it will create debate – and action – from Government to grass roots.

In creating this Manifesto, we followed three basic principles:

- ✓ Giving patients a proper voice in the running of the NHS
- ✓ Medical decisions should be taken by medical staff and not by accountants
- ✓ Prevention is always better than cure.

Our proposals include giving all patients a proper voice by calling for:

- Hospital boards to be elected by the local population.
- A new local Independent Complaints Panel to deal with all patient complaints. The NHS should not be its own judge and jury.
- The creation of more local Patients' Councils with which PCTs must consult
- All NHS pilot projects to be run in conjunction with patient groups
- Scrutiny organisations overseeing the NHS to be elected by the local communities

We want to see universal criteria to provide the best possible treatment as determined by medical opinion irrespective of where the patient lives.

We believe community care needs a complete rethink and call on the Government to enter into contracts with organisations like Age Concern, Help the Aged etc to provide a regular visiting service for the long term sick and the elderly to provide help and advice. We are proposing that the independent or charity sector should be tasked with this role to get away from the idea of 'authorities prying into a patient's private life.'

We want schools to provide training in basic first aid and dietary management. We recognise the dangers of obesity and want GPs to provide free diet and exercise clubs.

To stop the fragmentation of the NHS we are proposing that all levels including Primary, Secondary, Dentistry, Mental Health etc should be managed and led by a single board.

We recognise that the country has serious financial difficulties and that some savings may be necessary but we believe that front line staffing levels (doctors, dentists, nurses etc) need to be enhanced not cut.

We are calling for a care service which does not compel a patient needing care to sell the family home. We also recognise that Elder Abuse should be treated just as seriously as Child Abuse.

It is our intention to circulate this Manifesto to all candidates in the forthcoming General Election. We have laid it out in a way which allows people to make comments on each proposal. We would be very pleased to receive your opinions and support for the various proposals.

You can contact us at:

Paul Mainwaring

Chairman

The Patients' Council, Atrium House, 574 Manchester Rd., Bury, BL9 9SW. Tel: 0161-766-9323.

E. Mail: paul@patientscouncil.org.uk

A PATIENTS' VOICE

1 NHS BOARDS DIRECTLY ELECTED BY LOCAL PEOPLE.

The closure of local hospitals highlights the problems of the centralising mentality, and is symptomatic of the lack of accountability, and the lack of any democratic say for local people in the process of planning local health service provision. Locally-elected health boards would address the democratic deficit in the process of local health service planning. The local input would be achieved by giving the Local Consultation Panels (Item 3 below) a substantial voice in appointing people to the NHS Board. We recognise that there is a considerable amount of work needed to establish this principle in practice but are seeking to establish the principle

2 SET UP AN INDEPENDENT COMPLAINTS PANEL.

At present anybody who is unhappy about the treatment they (or their relatives) have received must lodge their concerns with staff at the institution they are complaining about. The NHS is therefore its own judge and jury.

We are suggesting the setting up of a National Panel which would consist of Patient Representatives, Social Services, medical staff (not employed by the institution being complained about), a solicitor and representatives from the Medical Trade Unions (not local representatives). Patients would then bring their concerns to this Panel for consideration. The Panel would seek to find a mutually agreeable resolution at an informal (series of) meeting(s) and would have the power to award financial compensation. The process would operate to a series of fixed timetables. This would not in any way stop patients from taking legal action, but we believe this is often the only way patients can seek apology or redress and an independent 'user friendly' alternative might be more attractive.

3 SET UP A PATIENT CONSULTATION PANEL.

The panels would operate on a tiered basis to enable full consultation at the different levels of NHS management. Members of the consultation panels would have training to enable them to negotiate with different levels of NHS management which would have fixed timetables for completing the consultation.

We would suggest that the Patients' Council be used as a template for setting this system up.

All NHS planning and operation would come within the jurisdiction of these panels.

4 N.I.C.E TO HAVE PATIENT REPRESENTATION.

Drawn from the Consultation Panels. See Item 3 above. (NICE – National Institute for Health and Clinical Excellence is the body which advises Government on the use of new drugs)

5 ALL NHS PILOTS SHOULD BE RUN IN CONJUNCTION WITH NON-POLITICAL, NON-INVOLVED PATIENT GROUPS OVER A SUITABLE PERIOD IN A SPECIFIED AREA/ZONE.

We believe that too much money is wasted running short-term pilot projects across several locations and patient experience/input is rarely gathered. Longer, one off pilots would be more cost effective and get to the core of the problem.

6 THE SCRUTINY BODY SHOULD BE ELECTED ON A 3 YEAR BASIS BY THE COMMUNITIES AND INVOLVE THE EXPERIENCE OF LOCAL BUSINESS PEOPLE.

NHS professionals are unelected. We believe that they should be held to account by a range of people, including those with business acumen.

B PREVENTATIVE MEASURES

7 INCREASE AWARENESS AND EMPHASISE EARLY DIAGNOSIS OF MEDICAL PROBLEMS.

Boost screening services and educational measures and provide them in a community setting.

8 OPPOSE ALL MASS MEDICATION e.g FLUORIDATION.

We are opposed to the contamination of our water with an industrial waste product irrespective of the so-called dental health benefits.

9 ENCOURAGE PHYSICAL FITNESS, INCLUDING FREE SPORTS COACHING AND WEIGHT MEASUREMENT.

We call for free sports facilities, during school hours, for all children, protection of playing fields and strengthening the financial status of voluntary sports clubs by enabling them to apply for charitable status.

10 DWP/SOCIAL SERVICES TO CONTRACT WITH VOLUNTARY SECTOR ORGANISATIONS (SUCH AS AGE CONCERN) TO REGULARLY VISIT THE LONG TERM SICK , PENSIONERS AND THE VULNERABLE TO ADVISE ON ACCESS TO GENERAL HEALTH AND WELFARE.

A charitable or voluntary sector organisation would be seen as 'being on the side of the individual' rather than a representative of 'authority on a spying expedition.' Community workers would befriend and help their clients access general health and welfare needs.

11 ALL GPs TO PROVIDE PERMANENTLY ACCESSIBLE FREE DIET AND EXERCISE ADVICE/FACILITIES.

Obesity is a major issue and we need to take steps to combat it.

12 EVERY CHILD UNDER THE AGE 16 TO BE PROVIDED WITH BASIC TRAINING IN FIRST AID AND GOOD NUTRITION.

Children need to grow up with a basic knowledge of First Aid and good nutritional practices.

13 EVERYONE IN THE UK TO BE PROVIDED WITH BASIC UNDERSTANDING OF HOW SOCIAL CARE WORKS AND GET TRAINING IN FIRST AID, SEXUAL HEALTH, DIETARY MANAGEMENT.

We know that cultural differences may mean a patient does not seek medical support until it is too late and they end up as an emergency hospital admission. This is unnecessary, dangerous and expensive.

14 HOSPITALS TO PROVIDE SHOWER AND CHANGING ROOM FACILITIES FOR STAFF.

We consider that there are hygiene risks to staff travelling to and from work in their hospital uniforms and that facilities should be provided for staff to change into or out of their uniforms on arriving or leaving the hospital. Provision to clean the uniforms on site will also be required

C STAFFING

15 FRONT LINE STAFF (DOCTORS, DENTISTS, NURSES) SHOULD CURRENTLY BE EXEMPT FROM ANY NHS CUTS.

In the current financial circumstances there will be pressure to make savings in the NHS. We believe that the front-line staff (doctors, dentists, nurses) should be exempt from these cuts and that in many cases believe their numbers need to be increased.

16 ADDRESS UNDER-STAFFING IN NHS BY GIVING A SUBSTANTIAL PAY RISE FOR NURSES AND PUTTING MORE EMPHASIS ON HANDS-ON TRAINING FOR NURSES RATHER THAN COLLEGE-BASED TRAINING.

The recent emphasis on college-based training is putting off many people who would be good nurses, but who either don't have the qualifications, or who feel intimidated by the college-based emphasis. Older people, who have the life-experience and communication skills to make good nurses but who don't want, or can't commit, to a college-based curriculum are disadvantaged. The NHS needs this kind of experience and a college-based qualification does not necessarily ensure that the nurse will have the communication skills, or hands-on ability to do the job. It takes a certain kind of person to be a good nurse.

17 APPOINT LINE MANAGEMENT WHO HAVE DIRECT, GENUINE, RELEVANT EXPERIENCE IN THE FIELD THEY ARE MANAGING

We believe it is a mistake to allow 'career' managers to run services they do not fully understand

18 SLASH UNNECESSARY BUREAUCRACY AND ENCOURAGE A NEW LOOK AT PROVEN STRATEGIES IN WARD MANAGEMENT.

To ensure optimum patient care. For example, the older forms of ward management, while more institutional, had the advantage of sharing the workload more evenly between the nurses, enabling them to work as a team to ensure all the basic tasks were getting done. New forms of management can lead to individual nurses becoming overloaded, while looking after several 'clients' at once. This can lead to a sense of isolation among nurses and lower morale.

D HEALTH CARE

19 CREATE SINGLE HEALTH CARE AUTHORITIES WITHIN GIVEN AREAS COVERING PRIMARY, SECONDARY, DENTISTRY, MENTAL HEALTH ETC TO RUN THE NHS WITH A BOARD STRUCTURE WHICH ACCURATELY REFLECTS THE COMMUNITY WITHIN THAT AREA

We believe this is a publicly acceptable way to cut bureaucracy if coupled with a Board (or governing) structure which accurately reflects the composition of the local population.

20 END THE POSTCODE LOTTERY OF AVAILABLE TREATMENT BY STANDARDISING LEVELS OF NHS TREATMENT TO BE AVAILABLE NATIONWIDE.

We are aware of a number of so-called 'postcode lotteries' within the NHS. We believe that optimum treatment should be available regardless of where a patient lives.

21 PCTs TO BE FORBIDDEN FROM VETOING/RESTRICTING THE USE OF DRUGS AUTHORISED BY NICE

Once NICE has certified that a drug is effective all decisions about when and for how long it should be used should be left to clinicians to take based purely on the grounds of medical effectiveness and informed patient wishes. PCTs should not be involved. We are aware that recent measures have moved in this direction but the issue needs to be monitored.

22 NHS DENTAL SERVICES TO BE UNIVERSALLY AVAILABLE.

Additional dental services are still required in many communities.

23 OUT-OF-HOURS SERVICE: PROVIDE AN EFFICIENT, QUALITY SERVICE WHICH OPERATES 24 HOURS A DAY, 7 DAYS A WEEK AND INCLUDES PROVISION OF HOME VISITS PROVIDED BY STAFF WITH ACCESS TO GP RECORDS.

We believe advances in technology being applied in the NHS make better out of hours care an achievable target. We are also aware of having to queue in all weathers outside G.P surgeries to get an appointment

24 APPOINTMENTS: ALL PATIENTS SHOULD HAVE URGENT ACCESS TO A GP WITHIN 12 HOURS AND NON-URGENT ACCESS WITHIN 24 HOURS. IT SHOULD ALSO BE POSSIBLE TO BOOK APPOINTMENTS BY PHONE

Our research into A+E attendance clearly shows that easier access to GPs would significantly reduce the number of people seeing A+E as their only route to out of hours treatment. This would reduce the burden on A+E and reduce overall costs.

25 DENTISTS WHO CANCEL APPOINTMENTS WITHOUT GIVING REASONABLE NOTICE SHOULD PAY COMPENSATION TO PATIENTS

We are aware that dentists charge patients for failing to keep appointments. This should work both ways with dentists paying compensation if they cancel an appointment without giving reasonable notice.

26 MAINTAIN LOCAL SERVICES.

Our priority is to ensure 24 hour care for local people, and especially to provide optimum emergency cover. This means looking closely at service delivery. Urgent care centres close to communities may be a better model than full blown A+E departments in every hospital. However, hospitals should not be closed until new replacement facilities are available and proven to be accessible and operating efficiently.

27 OUTLAW AGE/LIFESTYLE DISCRIMINATION IN THE NHS

Patients should receive the appropriate treatment based only on a medical assessment of their condition plus the informed wishes of the patient. A patient's age or lifestyle should have no bearing on this decision

28 PERSONAL AND NURSING CARE. PEOPLE TO HAVE ACCESS TO PERSONAL AND NURSING CARE FREE AT THE TIME OF NEED.

We call for older people to have access to free personal and nursing care. People who are no longer able to look after themselves should not be forced to sell their possessions to fund their care needs. Everyone in work should pay the same levy to completely fund their care needs

29 WE TOTALLY OPPOSE THE SECTION OF THE GOVERNMENT GREEN PAPER 'SHAPING THE FUTURE OF CARE TOGETHER' WHICH DEALS WITH FINANCE. ATTENDANCE ALLOWANCE AND DISABILITY LIVING ALLOWANCE SHOULD BE AWARDED STRICTLY ON THE BASIS OF MEDICAL NEED.

If a person has the misfortune to qualify medically for Attendance Allowance or Disability Living Allowance then they should receive the benefit without a question of a means-test.

30 DRUGS SHOULD BE PRESCRIBED STRICTLY ACCORDING TO MEDICAL REQUIREMENTS NOT JUST TO "KEEP A PATIENT QUIET".

We know some GPs prescribe drugs to some 'nuisance' patients to keep them content. This is a burden the NHS does not need. GPs should be able to refer these patients for counselling and be supported for refusing to prescribe unnecessary drugs.

31 SCRIPTSWITCH SYSTEM TO BE INTRODUCED NATIONWIDE.

Whereby generic alternative medicines can be issued after consultation with the G.P. and the patient where the alternative is cheaper than the brand-named product but is still approved by NICE. This will need to be introduced gradually starting when a new drug is prescribed. The Patient should, in consultation with the Doctor, have the right to revert to the original medication in the event of an adverse reaction. Only one medication should be changed at any one time to allow the effects of the change to be evaluated. Doctors/Pharmacists should always discuss the possible side-effects of Medication being prescribed. We are also aware that the licensing regulations with particular regard to “bulking agents” in Europe are more relaxed than those in the UK and the use of the various “Bulking Agents” in the alternative products will need to be carefully controlled. We also believe that there will be a role for “Drug Clinics” (See Para 33 below) in monitoring this system

32 PRIORITISE SPENDING ON BASIC MEDICAL AND SURGICAL RESOURCES.

Nurses report basics such as pillows and blankets are becoming a scarce resource.

33 PROVIDE A COMPREHENSIVE NETWORK OF DRUG TREATMENT CLINICS.

These would not only treat drug addictions and substance abuse but would also reassure patients about the drugs prescribed by doctors/consultants.

34 ALL NEW-BUILD HOSPITALS SHOULD BE DESIGNED ON THE BASIS OF ADEQUATE SINGLE ROOM ACCOMMODATION

We believe that people in hospital should receive respect with regard to privacy in their treatment. We would like to go further and provide a substantial element of single room accommodation in ALL HOSPITALS. However we are not convinced that this is financially viable.

35 HOSPITALS TO RE-INTRODUCE ‘DAY ROOMS’

We believe that patients need somewhere other than their bed where they can go and relax on comfortable chairs away from their bed

36 HOSPITALS TO PROVIDE SEGREGATED SMOKING FACILITIES

We believe that smoking is an addiction and to try to force people to stop smoking will only add withdrawal symptoms to whatever other complaint has forced them into hospital. Further you only have to look at the entrance to any hospital and you will find the ground covered with cigarette ends and have to force your way through a cloud of smoke and a horde of smokers (many in wheelchairs or carrying other medical equipment) to get into the hospital. These patients standing outside the hospital in all weathers cannot be improving their rate of recovery.

E SOCIAL CARE

37 CAR- PARKING FEES AT HOSPITALS TO BE ABOLISHED FOR PATIENTS, VISITORS AND CARERS.

People attending hospitals either as patients or visitors should not be charged for parking.

38 PROVIDE FREE TRANSPORT FACILITIES TO HOSPITALS FOR PATIENTS, VISITORS AND CARERS.

As hospitals now tend to specialise, patients and visitors will inevitably be faced with increasing travel costs. We believe this is effectively a tax on health.

39 SUPPORT A PROGRAMME OF BUILDING NEW COUNCIL RUN, HIGH QUALITY RESIDENTIAL NURSING HOMES.

To relieve the burden of elderly patient care on the NHS.

40 ELDER ABUSE AND ABUSE OF THE MENTALLY HANDICAPPED TO BE TREATED WITH THE SAME SERIOUSNESS AS CHILD ABUSE.

People guilty of elder abuse should be liable to the same level of legal punishment as for child abuse, with sound and robust inspection processes to root out abuse and neglect in hospitals, care homes and the community.

41 FRONT LINE STAFF TO RECEIVE EXTENSIVE PATIENT-COUNSELLING TRAINING.

Front line NHS staff (nurses, doctors, consultants) regularly have to communicate with patients and their relatives in circumstances which are highly distressing (e.g. major long-term illness, death). They need to be thoroughly trained to do this sensitively and with compassion.

42 ALL NURSING HOME/HOSPITAL PATIENTS TO RECEIVE FULL RIGHTS UNDER UK AND EC HUMAN RIGHTS LEGISLATION.

There has recently been a case in the European Courts about whether someone living in a care home enjoyed the full human rights confirmed under European Human Rights Legislation. Just because an individual is unfortunate enough to have to move into a care home should not mean their Human Rights are denied.

43 ALL SHELTERED HOUSING SHOULD HAVE RESIDENT FULL TIME WARDENS

People go into Sheltered Accommodation because they need some support. We cannot assume that these people will only need the support 9-5 or will always be able to operate some sort of emergency call-out system

F BENEFITS/FINANCE

44 IMMEDIATELY INCREASE LONG TERM BENEFITS (e.g RETIREMENT PENSION, WIDOWS' PENSIONS) TO A LEVEL AT LEAST EQUAL TO POVERTY LEVEL.

There is a £45 billion surplus in the National Insurance Fund which should be used to increase basic benefits so that the benefit you have paid for is at least equivalent to that which you haven't contributed to.

National Insurance is basically an insurance policy you contribute to when employed to give a reasonable standard of living when you are unemployed. The money should not be used to fund capital projects.

45 IMMEDIATELY START INCREASING BENEFITS ANNUALLY IN LINE WITH THE GREATER OF AVERAGE EARNINGS INCREASE OR THE COST OF LIVING INDEX WITHOUT ANY TYPE OF MEANS TESTING

This link used to exist but was broken by the Government during the 1980s. If the link hadn't been broken the basic Retirement Pension would currently be about £165 per week. The Government has stated it intends to replace the link by 2014 but only if it is affordable.

46 WINTER FUEL PAYMENTS TO BE INCREASED IN LINE WITH THE INCREASE IN THE COST OF FUEL SINCE THE BENEFIT WAS FIRST INTRODUCED.

Despite the massive increase in fuel prices this benefit has never been increased since it was first introduced. People cannot effectively budget on the off chance of a Government handout.

47 SCRAP THE OVER 80 PENSION ADDITION AND PUT THE MONEY INTO PARA 39 ABOVE.

This payment is so small (25p per week) as to be irrelevant. It should be absorbed into a proper basic State Pension.

48 SUPPORT FAMILIES WHO LOOK AFTER THEIR OWN ELDERLY.

If families are looking after elderly relatives at home then they should be supported both financially and physically (help and advice) by the state because they are taking the burden off the NHS. We support provision of extra benefits to enable care of the elderly at home (such additional benefits to be ignored in any means testing process).

49 FULLY FUND HOSPICES.

We believe that Hospices should get the full cost of caring for patients who would otherwise be taking up beds in hospital wards. At the moment they currently get only a small portion of the costs. The NHS should pay a fixed tariff to the Hospice for all patients who would otherwise be taking up NHS beds.

50 PERSONAL CARE ALLOWANCE TO BE INCREASED TO £40 PER WEEK.

Patients in care homes receive a personal allowance of £20 per week and this figure has remained unchanged for a number of years. It needs increasing in line with inflation, backdated to the last time it was increased (if it ever has been). This means about £40 per week and then increased annually in line with other benefit payments.

G ALTERNATIVE THERAPIES

51 PROTECT NATURAL AND HERBAL REMEDIES AND FOOD SUPPLEMENTS, ENCOURAGE COMPLEMENTARY THERAPIES WITH SUITABLE SAFEGUARDS

These are currently under threat from EU legislation. Thousands of people find that these work for them.

Issue date :- 22/10/09