

Ms Nicola Sturgeon MSP
Deputy First Minister and
Scottish Cabinet Secretary for Health and Wellbeing
St Andrew's House
Edinburgh
EH1 3DG

11 November 2007

Dear Ms Sturgeon,

Thank you for the opportunity to respond to the Discussion Document: "Better Health, Better care".

Scotland Patients Association (SPA) believes better care for patients and their carers would produce better health outcomes, resulting in better quality lives, as well as being more cost effective in the long term.

In our response, SPA will reflect what we have gleaned from patients and carers, throughout Scotland, who have shared their thoughts and concerns with us.

SPA has been a self-funding association since 1982. The aim of SPA is to work with any organisation, including government, to improve patient care and continuity of care, as well as supporting patients and carers, when they feel most vulnerable and powerless as patients. To increase awareness of our association SPA is currently applying for registration as a company and a charitable status to continue this much need independent service.

Yours sincerely

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Page 1

Introduction:

SPA in general agrees with the broad principles set out in the discussion document "Better Health, Better Care" and the challenges to be addressed, in developing an action plan for the future of the NHS in Scotland, and the desire to sustain communities and address inequalities.

Patient feed back to SPA:

SPA has noted some common themes emerging from what patients think

need to be addressed within the NHS, if there is a serious intention to improve patient care.

These themes can be applied to all sections of this document.

For example, all the following are of equal importance and include; workforce planning, NHS complaints system, Ombudsman, attitudes of NHS staff to patients, the worry over lack of cleanliness in hospitals, and the fear of acquiring hospital infections. Transport issues, car parking charges, closure of hospitals that encourages fear of the consequences of greater distances to travel to other centres, especially in an emergency. The fear that the extra distance could cause death is worse the further away people are from an A&E department or casualty department attached to a general hospital. This fear is worse in remote and rural areas.

Most patients would make a plea to the Scottish Government not to close any facility until it has been proved beyond doubt that the NHS and patients can do without the old one and that a better service has been put in place.

Patients know there are not enough beds in our hospitals because they are the ones who have to wait in casualty or A&E or have their elective procedure cancelled, due to lack of a bed or because of yet another hospital infection reappearing, as they do with monotonous regularity.

Patients feel that decisions taken some years ago may have to be changed in the interest of patient safety and to restore their confidence in the NHS.

Patients understand that we are an aging population living longer with some complex medical problems. Patients do not like when they have their operations cancelled because emergency admissions have taken up beds. It is right that elective cases should be separated from the emergency ones.

Sometimes the elective procedure is more straightforward than the general health of the patient and because of this they will have to be admitted to hospital,
Page 2

prior to and after surgery, for the procedure. It would free up beds at the larger more specialist hospital if small general hospitals were attached to the new day hospitals, such as the Victoria and Stobhill in Glasgow. At present this is not intended but these decisions were taken years ago and a great deal may be evident that was not then. Certainly, these hospitals should not close as general hospitals until the others are up and running. **This would be in the interest of patient safety.** The same would apply to coronary care units and intensive care units, which provide a known excellent service to the community.

Staffing Levels and Work force planning:

Patients see how NHS staff are working at present and are aware that often there are too few nurses to cope with the number and type of patients and their needs.

Good “Workforce Planning” will be essential to the success of any plan to improve patient care.

Fewer hospital and community care beds means more patients being treated in the community.

Primary Care has always been a labour intensive area, especially at the extremes of age, young and old. **Preventing the deterioration of the health of any patient in their own home needs more highly skilled and experienced** district nurses, health visitors, as well as allied health professionals, general practitioners and clerical staff, **than before**. This will cost more but will be more cost effective in the long term.

People who are housebound often live alone and lack stimulation from people contact. Perhaps the only human contact is the NHS professionals, for the time they are with them.

It is important to keep patients physically fit and mentally healthy to prevent further illness and mental deterioration.

People who do not suffer from mental illness as a long-term condition can develop depression with other long-term conditions, such as chronic pain and lack of mobility to name just two.

A happy skilled workforce can only be achieved with the appropriate numbers of staff with experience in the skill mix, as well as fair remuneration for the work done. To raise staff morale, which is very low at present, will benefit patients too.

Page 3.

The role of the District Nurse and Health visitor:

Some Health boards such as Greater Glasgow and Clyde wish to shift all health visitors to looking after the age group 0 -19 years and their families. It was also suggested that they would not take part in immunisations, which seemed strange. The discussion document setting out this idea did so without discussing who would replace the health visitor, or look after the over 19 age group. The Health Board did accept that no decisions could be taken until the result was known, of the Scottish Government consultation document into “Community Nursing”.

All decisions about training of nurses and the numbers to be employed will affect the standard of care, which can be given within the community/primary care.

Continuity of care, which is most important in early diagnoses and therefore in the ability to keep sick people in the community, will also, be affected. It is important to say that treating more people in the community

should not be to the exclusion of the need to have some of these patients admitted to hospital from time to time throughout their illness.

Poor skill Mix:

This can lead to discontentment among the higher qualified staff. People who have very short training courses, and who are not trained nurses, may not be alert to when detrimental changes are taking place. When does a simple dressing become one that is not so simple, especially when hospital acquired infections are rife? The patient suffers if there is a delay in referring on to a more senior person.

Confidence and competency are not the same and it takes experience to know when one is not competent.

Winter Beds and Medical Beds:

Also affecting quality of care in the community will be the ability to increase winter beds when required for medical admissions. This becomes more and more difficult with the closure of general hospitals in favour of Day Hospitals. Hospice beds for palliative care and complex nursing needs are essential for patients who cannot be cared for adequately at home for all or some of the time.

Patients have great faith in the hospices, which are run by charities, now that this work is not accommodated for within the NHS. Patients are increasingly suspicious of private companies working for the NHS because they know shareholders have to receive a share of the company profit.

Page 4.

Listening to the Patients and Elected Health Boards:

SPA is pleased that this document accepts the importance of constructive dialogue with the people who are potential patients, or users, of the NHS and who often feel they are being ignored.

Health boards have used "People Involvement" sessions to get their message across and have been selective in what they have taken on board from patients. The latter feel that both sides have been talking to each other but that is all.

SPA agrees that to have elected health boards is a way to have more transparency to the decisions health boards take. It would also make patients aware of the challenges in providing care. There needs to be further debate.

Need for Understanding and Tender Loving Care and Respite:

"Burn out" of the very large carers population should be avoided at all costs. A carer who is not adequately cared for will become a patient and the cared may end up in hospital, or in full time care. Respite is essential especially now as the carers are ageing with the population.

Attitudes of NHS Staff:

Patients consider their health to be the most precious thing they possess. Illness is a great leveller, whether a person is rich or poor, or has a medical degree, becoming a patient can be quite frightening and lonely situation in which to be.

Patients need respect and a great deal of tender loving care, as well as high technology. Patients do not enjoy being “processed” through the NHS system because of shortage of beds and staff lack of time to speak to them because they are too busy.

Communication breakdown:

Patients feel this usually when communication breaks down between patients and their NHS professionals or between the professionals themselves. This often happens when NHS staff is overworked and each staff member thinks the other has discussed matters with the patient or their relatives, but no one has. When this happens, it makes patients angry because they feel incidental to the running of the hospital. It is no comfort to a patient to know if there were no patients, there would be no hospital or staff.

Page 5

Complaints procedures:

Despite many patients having pleasant and uncomplicated journeys through the NHS, many do not. Patients often feel powerless in a system which does not respond to them by accepting a concern immediately or that it may be justified as constructive in its criticism.

To improve the NHS it is essential to look at the complaints system, which does not work well. It is such a pity that it does not work well because the NHS ends up with a very dissatisfied, angry and often fearful patient, and relatives. This dissatisfaction is then spread by word of mouth.

Good businesses speedily address complaints, and in fact welcome them. Addressing what is wrong or perceived to be so pleases the customer and the business learns from a frank dialogue with the customer. Everyone should be happy and what is spread by word of mouth is complimentary.

Sick people and their relatives do not have the energy to deal with an unsatisfactory service, nor should they have to use up their precious energy in that way. Many patients do not complain because of this fact and the fear of repercussions if they need to return to hospital. Very sick people do not have time on their side and it is unforgivable not to note this with the greatest respect.

Complaints, which have been treated as unsatisfactory by the patient, can be passed on to the Ombudsman or even to litigation.

Spa is aware of at least one person who was told by the hospital that they could of course go to the Ombudsman if they were not satisfied but there was little point in doing so because the Ombudsman have so many cases and therefore it would take ages to deal with their complaint. Being told something like this pushes people into the despair of ever changing anything by constructive criticism. In the end, the patient and their family are left often too weary to take matters further.

Most patients and their carers do not wish to litigate but wish a problem they have been aware of to be corrected, so that it will not happen again to them, or to anyone else.

If the complaints system is not improved, it will be difficult to see how the NHS can successfully move forward.

Page 6.

Importance of Understanding Patient Journey:

Following every patient journey, which has been unpleasant for them, can tell the NHS staff the areas, which could be improved for the better. SPA feels that the NHS needs to conscientiously take on board the patient's concerns not doubting the fact that they do have a point. This would be a pleasanter approach for NHS staff and patients as partners in improving a service. The NHS would improve and it would help with workforce planning. The cost of litigation, to the NHS, might even markedly diminish.

When patients see too many people are waiting in A&E for an admission bed, they know this is happening with monotonous regularity, and it is clear to them therefore, that there are not enough beds. Why does the NHS management not come to the same conclusion?

Relatives are extremely concerned at the number of patients who have falls and if all are recorded. Assessing the number of patient falls in wards and in care

Homes should be more than a statistical exercise and should be urgently addressed. Falls should be a very rare accident and are an indicator of too few nurses able to supervise patients. This is not good care and at worst may cost the life of a patient.

Infection control:

The increased incidence of infection rates is also in part related to poor staffing levels and to high bed occupancy.

Frequently patients tell of intravenous drips leaking and becoming infected. It would be interesting to know how many drips are recorded as becoming infected and in what locations? It would be worthwhile to be able to prevent this happening for the patients' sake but it would be good to know how infection is happening and how it is spread. Veins should be considered as

precious lifelines.

Patients tell of taking in their own cleaning materials to clean bedside tables, hands, and sometimes to clean toilets, all in personal attempts to avoid acquiring infection. This should not be their worry.

Patients who are ex nurses are horrified to see the differences in ward cleanliness compared to when they were working.

So many people who understood the job description of what the Matron of the 1960s and 1970s did, would love to see that role as it was, return. A modern day matron is very different. There was only one Matron to a hospital and she patrolled everyday, checking that the patients were being looked after well.

Page 7.

Anyone found to be wanting was told off, whether they were nurses or doctors or patients. **It might be well be worth a pilot to compare the old methods with the new to see if it really was better.**

The change in the career structure of the nurses, which was implemented in the 1970's, is frequently blamed as the start of the decline to where we are now. Until it changed, the sister in a ward did not need to leave the ward for promotion. The sister's experience was invaluable to young doctors and nurses. Patients rarely got bedsores because a nurse would have been ashamed if her patients developed them.

Nurses were able to change out of outdoor clothes into their uniforms and the hospitals laundered them, the nurse did not take them home as they do today.

Patients rarely have bed baths these day, according to observations. Is this true?

Patients who do not like the frozen food imported from a distance often get their relatives to bring in food and the sisters in charge of the wards may not know about this. Should this be allowed? It is a pity that local farm produce is not cooked in our hospitals by chefs. Appetising food helps patients recover faster if it is high in nutrition.

Patients relatives turn up to see them when full of the cold. Should this be allowed?

Infection control will only be successful when NHS staff, patients, and the greater public understand how infection spreads and it becomes second nature to think in a hygienic way.

Washing hands is important but what do people do with there hands after washing and before washing them again?

A dirty toilet and washroom can be seen to be dirty but the frequently touched surfaces look apparently clean.

In the past many remember wards to be cleaner with the dedicated in house team. Beds were pulled out every day to be dusted and the floor behind

cleaned. The ward cleaner was responsible for her work and she took a pride in what she did as a valued member of the ward staff. Today there seem to be too few cleaners doing the work and few if any are dedicated to a specific ward. We know that some hospitals do better than others do.

Page8.

Pharmacy and Opticians:

Will play a greater role in caring for patients and as long as patients understand what they are signing up to that is fine. Confidentiality concerns some.

A large group of patients who are very anxious and worried about the changes in their care, are patients who have stomas. Until now Specialist nurses have carried out this care exceedingly well. It is intended that Pharmacists will do this very personal fitting in the future. Even if the pharmacists get training for this important work, it will take some time before they can match the skill of the specialist nurse. Meanwhile what happens to this patient's care?

The other concern is over confidentiality and accommodation. Not all pharmacies have private rooms in which to deal with something as personal as stoma care. The latter is yet another case of changing something, which was working well and to the great satisfaction of patients. **No change should take place unless it is a better service to the patient.**

Freedom of Speech Essential:

At present patients who complain are likely to be in the minority because of the fear of speaking out, and their own perception of what the consequences will be if they did.

NHS staff also do not feel free to speak out and this culture needs to change so as to allow a successful and efficient NHS to develop. Staff, who are determined to work to the high standard of the code of practice, of their profession, to which they have been trained, would welcome freedom of speech.

If freedom of speech is not permitted or encouraged, people are left with the impression there **is** something to hide.

Recruitment and retention are important to the NHS and could be marred by lack of freedom of speech.

Respondent Information.

I agree to question 2a on this form

Jean Turner, Chief executive of SPA.