

Consultation on a Patients' Rights Bill for users of the NHS in Scotland

General Comments

We welcome the opportunity to comment on this very important paper. Unfortunately with the very excellent and sometimes highly technical services offered by the NHS, some basic principles have been overshadowed and perhaps need to be restated and the balance redressed. The patient is a whole person, whose general health and wellbeing contributes to the healing process. Vitamins, minerals, counselling, gym prescriptions, placebos if necessary, can all contribute to how well a patient feels and GPs particularly probably need to take account of these factors. House calls were often a means available to the GP of identifying underlying problems within families – now very much a thing of the past.

Patients by definition are often not feeling their best when having to deal with healthcare professionals. What someone would feel no qualms about expressing when fit and well can become all too daunting when feeling unwell and often vulnerable. Therefore, we would suggest there need to be clear and easily accessible routes for patients to have – if wished or needed – a carer or advocate to speak on their behalf – or to help the patient understand what a healthcare professional is saying or the information being conveyed.

Question 1: The right to Access

A Patients' Rights Bill will ensure accessible and timely health services for all by laying out clear entitlements to:

- *in-patient and day case waiting time guarantee;*
- *a choice of appointment times;*
- *support for individual needs to enable access to care;*
- *equitable access, taking account of equality and diversity, economic and geographical issues;*
and
- *a decision regarding access to care that is transparent, accountable and clearly communicated.*

Patients will be responsible for:

- *attending agreed appointments.*

Do you agree with the inclusion of these entitlements and responsibilities? Do you agree that there should be a 12 week in-patient and day case waiting time guarantee as proposed in this paper from 2011? Is there anything you would like to add to the right to Access? What do patients and/or the NHS need to do to make this happen?

We would agree that there should be a maximum time period of 12 weeks for day case or in-patient treatment once agreed. We also suggest that it should be a legal requirement to **record** that agreement so that there is no confusion about dates. Any departure from this time should be mutually agreed and signed by both patient and clinician. However, 12 weeks will obviously be too long for certain conditions and it would seem sensible to relate the waiting time to the condition eg stroke 3 hours, cancer 14 days etc. This will carry resource implications, but is nonetheless required and may have to

be reached over a defined time (eg 5 years). It is also important to ensure that there is similar commitment to those who have long term conditions.

Some patients still find it difficult to access GP appointments within anything like a reasonable timescale. We would like to see the practice of being asked to phone back later, or in 2 days time, or even a month's time being made unacceptable. The whole system of appointments at GPs needs to be overhauled and brought into line so that patients everywhere can expect a similar standard of service. We do however recognize that not all patient groups are the same and therefore consideration of needs and investigation of requirements will need to be applied.

Geographical zoning of hospital areas needs careful consideration also. What might be convenient for clinicians or administrators, is not necessarily so for patients eg sending patients to St John's hospital in Livingston, for a patient living at Fairmilehead in Edinburgh, and who has no means of traveling there.

In stating that access to healthcare should be equitable etc (para 22), we suggest that there should be an explicit right to NHS dentistry for all those who need and want it across Scotland, and a duty for local Health Boards to see it is provided. In addition there are a number of complementary therapies which are available to those with their own resources, such as chiropractic, osteopathy, homeopathy and nutritional medicine to name only a few. We suggest that these should be offered on the NHS also, particularly where they fill an obvious gap (eg osteopathy and chiropractic, filling the gap between orthopaedic surgery and physiotherapy).

We agree that patients should be responsible for attending agreed appointments, but we suggest it might be prudent for hospitals to send reminder texts, or even phone calls, where the appointment has been made a number of weeks previously.

Question 2: The right to Respect

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- *be treated with dignity and respect;*
- *care provided in a manner that is responsive to their culture, beliefs and values;*
- *care that is responsive to the individual circumstances of their life, such as their age, disability, gender, race, faith or belief, or sexual orientation; and*
- *relief from suffering, including palliative care, that is dignified, comforting and supportive.*

Patients will be responsible for:

- *treating staff with dignity and respect; and*
- *not physically or verbally abusing staff.*

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Respect? What do patients and/or the NHS need to do to make this happen?

We welcome the reciprocal right to dignity and respect for patients and staff. From our experience as patients, this is enhanced by

- honest dialogue, especially about diagnosis,
- by staff introducing themselves or any colleagues they may have accompanying them and
- by staff acknowledging that patients have a choice.

We also suggest that it should never be the practice to use relatives to translate where a patient does not speak English.

One very helpful thing the NHS could do is to ensure there is proper liaison between Hospital Departments and palliative care teams who may be in the community or a hospice.

Question 3: The right to Safe and Effective Care

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- *safe and effective care provided by health care professionals who have the right training and skills for their job;*
- *care that is informed and clinically appropriate;*
- *effective continuity of care and appropriate referrals; and*
- *an environment where patients, staff and systems are working to ensure quality and patient safety.*

Patients will be responsible for:

- *complying with advice on medication and treatment; and*
- *raising legitimate concerns about the safety of their care.*

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Safe and Effective Care? What do patients and/or the NHS need to do to make this happen?

In para 34, the last bullet point states that a patient should be entitled to “*an environment where patients, staff and systems are working to ensure quality and patient safety.*” We suggest that “*working to*” is not strong enough wording. Patients wish to be treated in clean environments and not to contract infections which are endemic in hospitals. Richard Branson in his capacity as a vice-president of the Patients Association in England has recently called for hospital staff to be screened for infections such as MRSA. Lothian Health Board has indicated it wishes to screen patients for MRSA before coming into hospital. We suggest that hospital staff in Scotland, who are arguably more often in contact with all sorts of infections, should, as has been called for in England, also be screened – it would seem to be in everyone’s interest to do so.

We suggest that the NHS could help patients comply with advice on medication and treatment by making sure that medication is received at the right time. It is also suggested in this regard that when the hospitals make 6-monthly check-ups at intervals of 7 months (or more) – obviously for resource reasons, there needs to be proper dialogue or adjustment of timed appointments.

We also suggest that patients’ responsibilities should in addition to complying with advice on medication and treatment, include complying with any recommended lifestyle changes, where these are important for recovery.

Where patients, visitors or carers raise legitimate concerns (eg about cleanliness), these should be dealt with immediately.

As a group we are concerned that there is a growing tendency for drugs to be freely available from pharmacies (eg statins) but seemingly no obligation for GPs to be informed through any official channel. We think that there should be a statutory duty for pharmacists to inform GPs of any requests for significant medication, particularly those with long-term effects, such as statins, or the 'morning-after' pill.

Question 4: The right to Communication

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- *clear, accessible and appropriate communication throughout the period of care, but particularly when plans change or if something goes wrong;*
- *be told the names of the staff responsible for their care and how to contact them;*
- *be told when their care is being handed over to the another health care team or provider, with regard for confidentiality, wherever possible;*
- *translation or interpreting services;*
- *independent advice and support, or to an advocate or other supporter; and*
- *to ask questions¹⁴ and obtain information about diagnosis, treatment and care from members of the healthcare team.*

Patients will be responsible for:

- *providing information about their history, current treatment medication and alternative therapies directly or through their family, carer or other nominated supporter;*
- *informing their healthcare provider of any changes in their condition; and*
- *taking part actively and constructively in discussion and decisions about their health and health care.*

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Communication? What do patients and/or the NHS need to do to make this happen?

We would reiterate that we think it is important the advocacy services are in place for patients who may need them. The word 'alternative' implies 'instead of orthodox treatment'. We prefer the word 'complementary', which is more accurate.

In terms of what the NHS might do to improve communication, we should like to see more honesty about diagnosis and prognosis in terminal cases, with specialist training for those doctors and other healthcare professionals who have contact with patients in this situation.

We would suggest that in any consultation with a healthcare professional that it should be routine to explain the role of any observer or person accompanying the professional. For example, more than one of our members has experienced a GP telling a patient that they have a 'student' with them – without mentioning that the student in question is not studying medicine. Had this been made clear, the patient might have chosen not to have them present.

We would also appreciate having quality assured and regularly reviewed leaflets available to patients for various conditions. It would be helpful if these were available and distributed regularly as well as being available on the web. It would also be preferable if there were not separate leaflets for each Board area – sometimes there have been different approaches in different Board areas.

Question 5: The right to Information

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- *information communicated in a language or format that they can understand;*
- *information about their health and wellbeing, care and treatment;*
- *information about their maximum waiting time;*
- *information that satisfies them about the treatment and medication options open to them, including the possible risks and benefits;*
- *information about discharge and continuing health care arrangements when in hospital, including medication, care planning, timely and appropriate referrals, convalescence, rehabilitation, self care and end of life care;*
- *see information in their health records; and*
- *request that they be copied any letters, faxes or emails written by NHS staff about their care and treatment.*

Patients will be responsible for:

- *seeking and using information appropriately to support their own health, for example to enable self-care for minor conditions; and*
- *ensuring that they have the information to understand what they need to know about their care, and to provide consent to treatment.*

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Information? What do patients and/or the NHS need to do to make this happen?

In general we are content with the entitlements and responsibilities listed, so long as there is provision also for the information to be given to or received by a carer or advocate where appropriate.

Question 6: The right to Participation

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- *be involved in, and supported to make, informed decisions about treatment and care to the degree and extent that they choose;*
- *involve family, carers or other nominated support people in their health care treatment, decision-making, participation and communication;*
- *be involved in decisions about who will treat them and where;*
- *give informed consent prior to any procedure, with discussion of options available, expected outcomes for each option, and success rates and incidence of side-effects for each option;*

- *withdraw consent or refuse further treatment, even if previous consent has been given to the treatment or procedure;*
- *choose whether to participate in the teaching or training of clinicians or research activities;*
- *be supported to be involved in decisions about their health services - locally and nationally; and*
- *information about how well their health board is performing against standards and expectations.*

Patients will be responsible for:

- *asking for further information if there is any uncertainty about their care;*
- *giving informed consent or not; and*
- *participating constructively in decisions about healthcare and service where they wish to do so.*

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Participation? What do patients and/or the NHS need to do to make this happen?

We discussed whether ‘side-effects’ should properly be described as ‘adverse effects’. However, we were content to leave in the hands of professionals the judgement as to how much information about adverse reactions should be given to the patient.

Question 7: The right to Privacy

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- *expect that the collection, use, disclosure and storage of their personal health and other information will be undertaken in accordance with the needs of privacy and confidentiality, and remain confidential, unless legislation requires disclosure or they direct otherwise;*
- *health services that respect their privacy and confidentiality; and*
- *access to their health records.*

Patients will be responsible for

- *providing the information that is appropriate and relevant to treatment of their condition.*

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Privacy? What do patients and/or the NHS need to do to make this happen?

We agree that these entitlements and responsibilities are important. We think that it should be made easier for patients to have confidential interviews in hospitals without being overheard: where mere curtains between beds make this impossible, a separate room should be set aside in each ward for such interviews.

Patient information and records should only be seen by those who have a legitimate right to see them.

Patients have the right to expect their personal data to be protected at all times and for there to be a process to ensure robust and secure systems.

Patients should have to opt-in for their information to be passed on to other departments, organizations and hospitals etc. and not have to opt out as is the present case.

Question 8: The right to Independent Support and Redress

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- *have access to, and independent support for, processes to comment on the care they receive;*
- *receive information and support on how to provide feedback, lodge a complaint or seek independent advice and support;*
- *have their concerns dealt with properly and promptly;*
- *be informed of what has changed as a result of their feedback or complaint;*
- *have access to the independent public sector ombudsman; and*
- *have access to independent advice and support to support their patients' rights.*

Patients will be responsible for:

- *offering feedback on their health services in a positive and constructive way as far as possible.*

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to this right to Independent Support and Redress? What do patients and/or the NHS need to do to make this happen?

Most of our group had no knowledge of the Independent Advice and Support Service which we understand is run by officers of the Citizens' Advice Bureau (para 66). We would therefore suggest a far higher profile for the service and much wider dissemination of its existence and what services it can offer.

If patients are to be offered the opportunity to give feedback on health services, it would be helpful if not every comment was logged as a 'complaint'. The word 'complaint' carries very negative and serious connotations and sometimes all a patient would like to say is "it would be helpful if we tried to do this another way".

Question 9: Other Rights

Are there any other key rights which you think should be included in the Patients' Rights Bill? What do patients and/or the NHS need to do to make this happen?

One of our members suggested there should be a right for a patient (or their nominated representative), if wished, to be at a case conference where important decisions about their health are taken. These might be transplant decisions, drug therapy in terminal cases, the cases are many. There may from time to time be exclusions for legal reasons – depending on specific circumstances, however in general it would be a huge step forward for a patient to hear the reasons for decisions and give them an opportunity to correct any misleading misinterpretation of facts. There may of course need to be

safeguards for a patient's mental health if sensitive issues need to be aired. But it would greatly encourage healthcare professionals to show their honesty and transparency in how decisions are reached.

Since it is now routine for maternity patients in Lothian to carry their own notes, we think consideration should be given for this practice to be extended to other patients, particularly those with long-term conditions such as cancer, stroke, and heart disease, where it is not unknown for patients' notes to be mislaid between hospital departments. This would ensure continuity, and make for more efficient use of clinicians' time. We suggest that giving this option to patients, with a clear reminder that it is their responsibility to keep the record safe, would give the patient the sense of full participation in their own recovery, and a feeling of genuine partnership with clinicians. As this may be regarded as a very bold step we would suggest that a master record is maintained, at least until there has been research to show how effective it is for patients to keep their own records – and of course a master record may be required for legal reasons.

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