

Meeting of
Lanarkshire NHS Board
17 December 2008

Lanarkshire NHS Board
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SUBJECT: Patients' Rights Bill

1. PURPOSE

This paper is presented to the NHS Board to provide members with an overview of the Scottish Government's public consultation on the possible contents of the proposed Patients' Rights Bill and invites the Board to consider whether the proposed rights and responsibilities are comprehensive and appropriate.

2. CONTENT/SUMMARY OF KEY ISSUES

As signalled in "Better Health, Better Care" it is the Scottish Government's intention to introduce in 2010 a Bill to create a legal framework to support patients in knowing what their rights and responsibilities are; and to provide effective redress where they consider that their rights are not being fully delivered.

In order to develop this further the Scottish Government is currently undertaking a public consultation exercise on the possible contents of the proposed Patients' Rights Bill for users of the NHS in Scotland. The consultation paper can be found at www.scotland.gov.uk/Publications/2008/09/22091148/2 . The consultation period ends on 16 January 2009.

The consultation paper sets out patients' existing rights and entitlements, commenting that these are not always widely understood or exercised by patients. These existing rights and entitlements include legal rights as well as expectations derived Government policy and clinical standards and include, for example, to:

- refuse medical treatment
- consent to treatment
- see personal health record
- be treated without discrimination on grounds of e.g. race or disability
- be treated with dignity and respect
- be treated within maximum waiting time
- be involved in treatment choices
- be treated in a safe and clean environment.

It then moves on to describe those rights and responsibilities for possible inclusion in a Patients' Rights Bill. The proposed headline rights and responsibilities are replicated in Appendix I of this paper which also describes whether they are mirrored in current practice.

Of particular note are the following new proposed rights and responsibilities:

- The proposed Bill will include provision for a Charter of Mutual Rights which will set out how the rights will be delivered in practice and what patients' responsibilities are in relation to their use of health services
- Waiting time guarantees appropriate to a patient's condition will be legally binding; the Bill will set out the terms of the guarantee
- A participation standard will be developed to build on the existing community engagement guidance
- Every household will receive an Ownership Report on their rights and responsibilities; what services are available; and how well the NHS Board is performing against the participation standard
- Patients' Rights Officers will be established in every Board area, either in addition to the existing Independent Advice and Support Service or as an expansion of that service
- The possibility of establishing a no-fault compensation scheme will be explored.

3. ACTIONS

In undertaking this consultation exercise the Scottish Government seeks to test what might be incorporated into a Patients' Rights Bill, the intention being to make more explicit and succinct existing rights and responsibilities already provided for under legislation or derived from policy or clinical standards. The Scottish Government is also seeking views on whether there are any potential omissions.

The consultation paper suggests a number of proposed new rights and responsibilities on which Lanarkshire NHS Board may wish focus its discussion and reach a view on whether it wishes to support these.

The North and South Lanarkshire Public Partnership Forums were invited to share with the Board their views in this regard in order that these could be taken into account in the Board's response to the consultation document. At the time of writing their responses had not been received, although it is understood that they intend to respond directly to the Scottish Government with their thoughts on the consultation paper.

It should be noted that the proposed Patients' Rights Bill will itself be subject to consultation.

4. CONCLUSIONS

The Board is asked to consider whether there are any omissions from the rights and responsibilities set out in the consultation paper on the proposed Patients' Rights Bill and whether it would wish to support the proposed new rights and responsibilities.

5. FURTHER INFORMATION

For further information or clarification of any issues in this paper please contact: Shona Welton, Head of Patient Affairs, Telephone number 01698 245197.

Paul Wilson
Executive Director for Nurses, Midwives and Allied Health Professionals

Proposed Key Patients' Rights & Associated Responsibilities

Key Patients' Rights & Responsibilities	Entitlements as set out in the Consultation Paper	Examples of Current Application
<p><u>Access:</u> Equity of access to NHS care</p>	<p><u>Rights:</u></p> <ul style="list-style-type: none"> ➤ Inpatient and day case waiting time guarantee ➤ Choice of appointment times ➤ Support for individual needs to enable access to care ➤ Equitable access, taking account of equality, diversity, economic and geographical issues ➤ Decision regarding access to care that is transparent, accountable and clearly communicated <p><u>Responsibility:</u></p> <ul style="list-style-type: none"> ➤ Attending agreed appointments 	<ul style="list-style-type: none"> ➤ Guarantees are current Government policy; the consultation paper sets out headline criteria and reduced time frames, and indicates that these would be legally binding ➤ This is current Government policy ➤ The examples given of interpreting services and patient transport are currently in place ➤ This is currently covered by equalities legislation and NHS QIS standards ➤ This forms part of professional standards and, for example, the Senior Charge Nurse/ Team Leader objectives ➤ Consideration should be given to including in the Bill an additional responsibility for notifying the NHS Board promptly when patients are unable to attend an agreed appointment

<p><u>Respect:</u> Respect, dignity and consideration for the individual</p>	<p><u>Rights:</u></p> <ul style="list-style-type: none"> ➤ Be treated with dignity and respect ➤ Care provided in a manner that is responsive to culture, beliefs and values ➤ Care that is responsive to the individual circumstances of patient's life, such as their age, disability, gender, race, faith or belief, or sexual orientation ➤ Relief from suffering, including palliative care that is dignified, comforting and supportive <p><u>Responsibilities:</u></p> <ul style="list-style-type: none"> ➤ Treating staff with dignity and respect ➤ Not physically or verbally abusing staff 	<ul style="list-style-type: none"> ➤ This forms part of professional, NHS QIS and local customer care standards ➤ This forms part of professional, NHS QIS and local customer care standards; and is covered by equalities legislation ➤ This forms part of professional, NHS QIS and local customer care standards; and is covered by equalities legislation ➤ This forms part of professional standards and NHS QIS standards; and is encompassed within local work to embed the Liverpool care pathway ➤ This is covered by existing legislation ➤ This is covered by existing legislation
<p><u>Safety:</u> Safe and effective care and treatment</p>	<p><u>Rights:</u></p> <ul style="list-style-type: none"> ➤ 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 ➤ An environment where patients, staff and systems are working to ensure quality and patient safety 	<ul style="list-style-type: none"> ➤ This forms part of national policy (Leading Better Care), professional, organisational and NHS QIS standards ➤ This forms part of professional, organisational and NHS QIS standards ➤ This forms part of professional, organisational and NHS QIS standards ➤ This forms part of professional, organisational and NHS QIS standards

	<u>Responsibilities:</u> <ul style="list-style-type: none"> ➤ Complying with advice on medication and treatment ➤ Raising legitimate concerns about the safety of their care 	
<u>Communication:</u> Which is clear and appropriate	<u>Rights:</u> <ul style="list-style-type: none"> ➤ 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 ➤ Be told when their care is being handed over to 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 ➤ Ask questions and obtain information about diagnosis, treatment and care from members of the healthcare team <u>Responsibilities:</u> <ul style="list-style-type: none"> ➤ Providing information about their history, current treatment medication and alternative therapies directly or through their family, carer or other nominated 	<ul style="list-style-type: none"> ➤ This forms part of professional, NHS QIS and local customer care standards; and, for example, the Senior Charge Nurse/ Team Leader objectives ➤ This forms part of professional and local customer care standards ➤ This forms part of professional standards ➤ This forms part of professional, NHS QIS and local customer care standards and is covered by equalities legislation ➤ This is currently required under the NHS Complaints procedure; the availability of advocacy is also a requirement of mental health legislation ➤ This is covered by legislation on consent to treatment

	<p>supporter</p> <ul style="list-style-type: none"> ➤ Informing their healthcare provider or any changes in their condition ➤ Taking part actively and constructively, where possible, in discussion and decisions about their health and health care 	
<p><u>Information:</u> About services and care and treatment options</p>	<p><u>Rights:</u></p> <ul style="list-style-type: none"> ➤ 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 guarantee ➤ Information that satisfies them about the treatment and medication options open to them, including the possible risks and benefits ➤ Information about continuing health care arrangements when in hospital and discharge, including medication, care planning, timely and appropriate referrals, convalescence, rehabilitation, self care and end of life care ➤ See information in their health records ➤ Request that they be copied any letters, faxes or emails written by NHS staff about their care and treatment 	<ul style="list-style-type: none"> ➤ This forms part of professional, NHS QIS and local customer care standards; and is covered by equalities legislation ➤ This forms part of professional and NHS QIS standards; and is covered by legislation on consent to treatment ➤ This is current Government policy ➤ This forms part of professional and NHS QIS standards and is covered by legislation on consent to treatment ➤ This forms part of professional and NHS QIS standards ➤ This is covered by Data Protection legislation ➤ This is covered by Data Protection legislation

	<p><u>Responsibilities:</u></p> <ul style="list-style-type: none"> ➤ Seeking and using information appropriately to support their own health, for example to enable self care for minor conditions ➤ Ensuring that they have the information to understand what they need to know about their care, and to provide consent to treatment 	
<p><u>Participation:</u> In decisions about health and services</p>	<p><u>Rights:</u></p> <ul style="list-style-type: none"> ➤ Be involved in, and supported to make, informed decisions about treatment and care to the degree and extent they chose ➤ 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 	<ul style="list-style-type: none"> ➤ This is covered by legislation on consent to treatment; and by professional and NHS QIS standards ➤ This is covered by legislation on consent to treatment; and by professional and NHS QIS standards ➤ This is covered by legislation on consent to treatment; and by professional and NHS QIS standards ➤ This is covered by legislation on consent to treatment; and by professional and NHS QIS standards ➤ This is covered by legislation on consent to treatment; and by professional and NHS QIS standards

	<ul style="list-style-type: none"> ➤ Be supported to be involved in decisions about their health services – locally and nationally ➤ Information about how well their health board is performing against standards and expectations <p><u>Responsibilities:</u></p> <ul style="list-style-type: none"> ➤ Asking for further information if there is any uncertainty about their care ➤ Giving informed consent or not ➤ Participating constructively in decisions about healthcare and services where they wish to do so 	<ul style="list-style-type: none"> ➤ The proposed Participation Standard would build on existing guidance on community engagement in service design and delivery ➤ The proposed Ownership Report to be delivered to every household would build on information currently published by the Scottish Government and by Boards; this is also covered by Freedom of Information legislation
<p><u>Privacy:</u> And confidentiality of personal health and services</p>	<p><u>Rights:</u></p> <ul style="list-style-type: none"> ➤ 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 ➤ Access to their health records 	<ul style="list-style-type: none"> ➤ This is covered by Data Protection legislation ➤ This is covered by legislation on consent to treatment and by professional and NHS QIS standards ➤ This is covered by Data Protection legislation

	<p><u>Responsibility:</u></p> <ul style="list-style-type: none"> ➤ Providing the information that is appropriate and relevant to treatment of their condition 	
<p>Independent Support and Redress: By commenting on care and having concerns addressed</p>	<p><u>Rights:</u></p> <ul style="list-style-type: none"> ➤ 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 ➤ Have access to independent advice and support to support their patients' rights <p><u>Responsibilities:</u></p> <ul style="list-style-type: none"> ➤ Offering feedback on their health services in a positive and constructive way as far as possible 	<ul style="list-style-type: none"> ➤ This is currently required under the NHS Complaints procedure and NHS QIS standards ➤ This is currently required under the NHS Complaints procedure and NHS QIS standards ➤ This is currently required under the NHS Complaints procedure ➤ This is currently required under the NHS Complaints procedure and NHS QIS standards ➤ This is currently required under the NHS Complaints procedure ➤ This is currently available through the Independent Advice and Support Service. The proposed creation of separate Patients' Rights Officers in every Board area could lead to confusion amongst patients and their families. The proposed no-fault compensation scheme would require detailed work-up