



# The Scottish Women's Convention

## Response to the Scottish Government Consultation on a Patients' Rights Bill for users of the NHS in Scotland

This paper contains the Scottish Women's Convention response to questions within the Consultation Document which have a particular relevance to women.



The purpose of the Scottish Women's Convention (SWC) is to communicate and consult with women in Scotland to influence public policy. Through the Convention's policy work, round table and celebratory events the SWC strives to have contact with women and relevant organisations. The SWC aims to provide an effective way of consulting with a diverse range of women in Scotland.

The Scottish Women's Convention has a network of over 300,000 women from relevant organisations throughout Scotland.

## **QUESTION 1: The Right to Access**

In summary, 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
- § 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 within the overall 18 week referral to treatment target there should be a 12 week in-patient and day case waiting time guarantee 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?

## **SWC Response**

The SWC in principle welcomes ongoing efforts by the Scottish Government to reduce surgical day/inpatient treatment waiting times.

Our various consultations with women throughout Scotland confirm that treatment timeliness is a concern for them. However, it is also widely recognised by the majority of women we have spoken to that the National Health Service Scotland (NHSS) provides a responsive and dedicated service especially in treating emergency cases. In urgent situations access to the service is valued for its effectiveness, the right of all to access, and being free at the point of that access and through continued treatment.

The proposals confirm that clinicians will continue to have the flexibility and freedom to set the clinical priority (paragraph 17) and as acknowledged above many in society would agree with this stipulation being reasonable. What the proposals do set out is a guarantee that once in-patient or day case treatment has been agreed as the most appropriate way forward there will be a maximum waiting period of 12 weeks to treatment. This guarantee will operate within the overall referral to treatment (RTT) patient journey time of 18 weeks which is the proposed target

standard to be met by 2011 as set out in the *NHS Better Health Better Care Action Plan. 3.7 Timeliness.*

Undoubtedly this is a commendable target and one which the SWC would fully support in reducing part of the overall patient care pathway time from RTT. However, the SWC believe it is an ambitious target. The initiative to reduce RTT standards from 36 to 18 weeks was only introduced in the spring of 2008 and Health Boards have until 2011 to comply. It could therefore be reasonably argued that RTT time limits of 18 weeks have not been proved deliverable. Offering guarantees – underpinned by legislation - for a 12 week limit, from agreement of treatment to admission, within this timescale could be premature.

The SWC believe that due consideration should be taken during consultation as to whether guaranteed 12 week delivery of treatment within a 18 week national RTT standard, while laudable, truly offers improved service or is merely a political response to an increasingly target/compliance culture.

The SWC acknowledge the investment of £270 million by the government to reduce hospital waiting times and the implementation of the 18 week reduction on the whole journey standard from 36 weeks. Nevertheless further investigation is warranted to assess the overall impact this level of investment will have on other aspects of health care which the people of Scotland expect to be delivered to maintain and improve their health.

It has been clear from consultation with women in Scotland that access to primary care and wider community health initiatives are of equal importance to them especially for those who are furthest away from social inclusion or have multiple needs. In this respect the proposals regarding guarantees on access may be too focused on hospital In-Patient interventions to the detriment of other patient treatment waiting times such as Physiotherapy, Infertility Treatment and Counselling to name but a few. Women have expressed frustration to the SWC that prolonged waiting times for treatment in such healthcare specialties or indeed local surgeries have a negative impact on both their conditions and perceptions of NHSS patient care.

If rights to access are to be enshrined in legislation the SWC believe that an opportunity to improve patient access should go beyond hospital (elective) in-patient or day case guarantees. Holistic treatment of individuals through Community Health Partnership working is becoming more successful in treating a number of long term conditions and waiting lists for referral to these services are prohibitively long in many areas. Are these going to be reduced and “guaranteed” by the proposals?

Legal rights regarding access and waiting times which are limited to some aspects of service may suggest to patients that “guarantees” are in fact an empty promise when they need to be underpinned by a legal right to redress.

The SWC approve of the need for any proposed Patients Rights Bill to include the requirement of an NHS Board to inform the patient of the steps they will take to meet guaranteed standards of timeliness for their treatment such as using services of other Health Boards or treatment overseas etc. (paragraph 21). However, we believe that more information is required in the passage of any legislation in order to evaluate this entitlement.

If a patient declines treatment in another Health Board area or overseas due to personal circumstances e.g. issues of childcare availability how will this impact their position on any waiting list? Will they be put back to the start of process or be unduly discriminated against in the queue for treatment?

This is a potentially important consideration for women as the main provider of childcare or kinship care especially for women in rural areas who in many cases already face extended time away from families due to distances away from hospital services. The SWC believe a gender based consideration would not be inappropriate in the allocation of patients to services outside their regions.

The SWC fully support the sentiments of paragraph 22 for inclusion in any proposed legislation on patient rights that access to healthcare must be equitable, appropriate and responsive to individual needs including age, disability, ethnicity, gender, religion or belief, sexual orientation and transgender status. We welcome the inclusion of rights for patients to the support necessary to enable them to access the care offered to them.

Finally the responsibility of patients to attend agreed appointment times is not unreasonable when considered against the broader impact on resources, other patients and ultimately taxpayers. However, placing a responsibility in legislation may worry individuals who may have to miss an appointment for legitimate reasons. The SWC have spoken to women who have actually notified services of an inability to attend a hospital appointment and had their consultation deferred for months. The SWC states that placing this responsibility on patients must have potential outcomes clarified in more detail.

## **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, values
- § responsive to the individual circumstances of their 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

Patients will be responsible for:

- § treating staff with dignity and respect
- § 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?

### **SWC Response**

The SWC has found that women taking part in their events who have experienced conditions such as poverty, unemployment, disability or illness confirm unanimously that protecting their right to respect and dignity is fundamentally important to them.

When the NHS was created 60 years ago the concept of dignity and respect were perhaps part of an unwritten code of conduct and it might be said mutuality of conduct between patient and practitioner taken for granted.

Society, behaviours and expectations change and initiatives and directives to ensure respect and dignity continue at the heart of healthcare in this country should be welcomed by society as a whole. Significant and well presented inclusions in publications such as: *The Patients Charter 1991 & 2000*, *The NHS and You 2005* and *Better Health, Better Care Action Plan 2007* demonstrate the strength of support by policymakers for the robust defence of what are basic human rights.

What does not change is the vulnerability people can feel when they are ill and SWC therefore commends Scottish Government recognition that a mutual NHS where patients have a right to be

listened to and have their views taken on board is an important step in empowerment for patients in achieving respect and ensuring their dignity is valued.

The SWC completely supports inclusion of these rights in any strengthening of a Patient Charter however legislation already exists which offers statutory rights on equality issues e.g. Gender, Race, Disability etc. and the SWC remain unconvinced that a Patients Rights Bill will offer more protection. It may give more “clout” to patient’s rights but does not elaborate on “how” they will go about exercising them in any detail.

When considering the consultation response to this question the SWC also reflected on possible examples of infringements to a patient’s dignity and respect which may be more difficult for patients to challenge perhaps due to the vulnerability of their position or the perceived threat of reprisal and the SWC would like to take this up in more detail in our response to *Q 8 – The Right to Redress*.

The SWC would like to state at this point that it is important that the right to dignity and respect is understood by all in the first instance. Some patients have complex communication problems. Any rights for them would be weakened considerably if there was dependence on the statutory frameworks rather than on the continued building of relationship improvement, staff training and education and vigorous monitoring standards.

A number of women the SWC engage with are also NHS workers and we would endorse the consultation paper statement that the vast majority of NHS employees carry out their duties with care and compassion and a strong vocational commitment to their role. Any proposed legislation on Rights or Responsibilities regarding Respect and Dignity must consider if in fact the proposed bill will improve or enhance relationship dynamics between patient and practitioner.

The SWC suggest, for patients who are most vulnerable, improving rights to respect and dignity is about changing society’s attitude towards them in the first instance. Without this fundamental cultural shift merely giving them a statutory right will not improve their patient journey in the Health Service or in Scottish society as a whole.

On turning to the Patients Responsibilities in Q 2 the SWC strongly support the need to ensure staff can perform their duties in an environment of respect and dignity in whatever capacity they carry out their work. As approx 78 -80% of staff in the NHSS are women<sup>1</sup> the SWC are especially concerned that physically or verbally abusing staff is given zero tolerance by Health Boards and the Scottish Government and is prioritised in any strategy.

As Nicola Sturgeon said in the Parliamentary debate on the Patients’ Rights Bill on 6<sup>th</sup> November 2008 “*...it is much more difficult to place patients’ responsibilities in law than it is*

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<sup>1</sup> <http://www.scotland.gov.uk/publications/2008/12/30093950/1>

*to place patients' rights in law.*" Therefore, the SWC look forward to more transparency on how the proposals will ensure greater safety for employees.

The Emergency Workers Act 2005 and subsequent amendments is an important piece of legislation to support workers in front line services and it has resulted in prosecution and conviction of those who have abused care workers. The SWC hope the NHSS will continue to work with Trade Unions and other bodies to ensure that the protection of their workers is enhanced through every means possible including through these proposals if feasible.

The SWC would welcome clarity on the benefit of including Patient Responsibility in regard to the safety of staff and how it could be utilised to enhance a culture of respect towards workers in the NHSS. Would it ultimately encourage or enforce a zero tolerance approach to the harassment of NHS staff?

### **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
- § 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 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?

### **SWC Response**

Safe and effective care has been central to the ethos of the National Health Service since its inception and the SWC concur with the Scottish Government's position on the importance of ensuring that the standards of care and safety are maintained as the advancement of technology and knowledge expand services and expectations.

Undoubtedly the Scottish people will be reassured by the Scottish Government establishing the Scottish Patient Safety Alliance to reduce incidents of health care infection, adverse surgical incidents and adverse drug events. As women engaging with the SWC have also expressed concerns regarding health care infections we welcomed the government announcement of a further investment of £50 million towards tackling Healthcare Associated Infection (HAI) through measures carried out by an HAI taskforce.<sup>2</sup>

Public confidence in the care provide by the NHSS can only be made more positive through measures such as these and the SWC recognises the Scottish Government's desire to see rights in

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<sup>2</sup> Better Health , Better Care: NHS Scotland Action Plan 3.3 Patient Safety

respect of safety and effective care enshrined in legislation as a means of strengthening the effectiveness of the above initiatives and to encourage Health Boards to deliver. The SWC support the intention implicit in the proposals.

What the SWC would like to draw attention to in response to this question is the lack of any specific sanctions within the proposals which would punish those services who fail to deliver on the above issues or indeed other patient rights. There needs to be further explanation provided on what enforceable entitlements it will provide patients with in order to pursue their rights over and above what is currently available through the courts on issues of medical negligence for example.

The consultation document makes reference to the Scottish Government “favouring” a no fault compensation scheme as a way forward but that there is a need for further work on this. The SWC feel that until that work is undertaken it is difficult to comment further on whether it is useful to include these entitlements in a proposed Bill as it unclear what it would achieve.

Patient Responsibilities are to comply with advice on medication and treatment; and raise legitimate concerns about the safety of their care. These are sensible precautions which in a perfect world should be easy to abide by however the SWC are concerned that complications and conditions in the lives of some individuals and families make this an onerous task.

Undoubtedly the responses to this consultation will furnish the Government with an array of examples of what these complications or conditions might be therefore the SWC example will be brief but not exclusive.

- Families who live in poverty and social exclusion suffer deprivation on many levels. Efforts to comply with treatment advice are frequently a conduit for further anxiety and feelings of exclusion.
- A person suffering from mental illness remembering to take medication.
- A person with communication difficulties understanding complicated instructions when they are unwell.
- Parents may use their discretion and refuse an MMR for their child. Is this a failure to comply with advice?

How can every patient know if a concern about the safety of their care is legitimate or not? What are the criteria for assessing this? Indeed who decides on the legitimacy?

The SWC feel that it will greatly concern many families that such responsibilities will be put within a legal framework and could have a detrimental impact on them seeking help. This would be a strongly counter productive to the efforts of the Public Health Sector who are endeavouring to put health inequalities at the heart of their agenda.

The SWC also note the consequences of them not complying with this responsibility have not been set out in the proposals.

#### **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 a qualified interpreter,
- § independent advice and support, or to an advocate or other supporter
- § to ask questions<sup>1</sup> 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.
- § taking part actively and constructively in discussion and decisions about their health and health care

<sup>1</sup> E.g. by being provided with the HRIS leaflet Its OK to ask: see [www.hris.org.uk](http://www.hris.org.uk)

Do you agree with the inclusion of these entitlements and responsibilities?  
Is there anything you would like to add to the right to Communication?

#### **SWC Response**

The failure to communicate and delayed or inaccurate communication is without doubt one of the main complaints the SWC hear from women on issues of health.

The importance of continued communication improvement cannot be underestimated in providing better partnership working between patient and health worker and a mutually

improved relationship during the patient journey. This can only improve clinical outcomes and provide the best value for NHSS budgets.

E Health initiatives to communicate with patients, especially those living with long term conditions have been enthusiastically received by women the SWC have spoken to on the whole and is of considerable benefit in equalising elements of care to those in more remote rural communities.

Overall the key points listed as patient communication rights are commendable and the SWC support the proposals underlining of the importance of good communication.

The SWC believe that putting communication rights and responsibilities within a legal framework could be complicated not least because “clear, accessible and appropriate” communication will mean very different things to different people.

- A clinician or specialist may view the contents of a letter or the details of a conversation very differently from a patient.
- Various mediums of communication can be a positive experience for some and a negative one for others.

Feedback from women we speak to supports the view that efforts made by Health Boards to inform the public on aspects of health generally, such as campaigns on smoking or diet, are positive communication tools. Some women, on the other hand, highlighted experiences of a less effective level of communication when it involves personal support.

We are therefore not surprised that the NHSS have at various times indicated that issues of interaction cause a significant level of complaints often for minor breakdowns in communication.

The SWC suggests that placing rights such as these in a legal framework might be less effective and meaningful to patients than entering into personal contracts with individuals at the commencement of treatment.

It could be said that patients are more likely to be actively and constructively involved in discussion and decisions about their health and healthcare if they believe the communication commitment is at a personal level rather than the dictate of blanket provision.

It would be helpful for the purposes of consultation contribution if the Government’s definition of communication could be expanded upon as the SWC are unclear as to whether the exercising

the right “to ask questions” would be effectively responded to by being provided with the HRIS leaflet<sup>3</sup>.

### **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
- § 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
- § 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?

### **SWC Response**

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<sup>3</sup> Health Rights Information Scotland

Women sharing experiences of healthcare with the SWC have consistently highlighted the positive aspects of engagement when information is sought and communicated in a timely and understandable format. This demonstrates to the SWC the importance that many individuals place upon being informed and consulted.

Government aspirations of a mutual Health Service which is partnership driven are outlined by the Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP in her introduction to the consultation paper and the SWC believe that the constructive sharing of information is vital if this aspiration is to be achieved.

The SWC therefore believe the inclusion of information rights is important and that the proposed rights referring to information are reasonable and relevant.

The only point we would like to draw out is in the summary statement (paragraph 45)

- A patient is entitled to: “...information that satisfies them about treatment and medication options open to them.”

The SWC believe it would be beneficial to ensure there is no ambiguity as to the extent “satisfies” is understood by the patients or a health care provider.

In response to the patient responsibilities set out in this section the SWC are not convinced that all patients will have the confidence or means to seek information or assess what is appropriate self help for their conditions.

The SWC believe that due to conditions of social deprivation, lower quality of health continues to pose a barrier to pro-active care where stronger communication links are more readily achievable. It can be harder to impose responsibilities on individuals who require the more intense support of re-active care.

We are therefore not confident the eradication of health inequalities in Scotland has been achieved to a degree where it would be appropriate to embed patient communication responsibility in a legal framework.

Putting the onus on patients to ensure they have enough information to understand what they need to know about their care is potentially very complex. How can complying with this responsibility be measured or assessed given the non-homogenous nature of the population?

### **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
- § 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

§ 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?

### **SWC Response**

The SWC respect the Scottish Government's efforts to strengthen and extend patient rights and working towards greater partnership in care is a goal that the SWC can support.

Participation of patients and indeed the wider population in their health care and wellbeing is undoubtedly an important factor in achieving this. The SWC suggest however that giving people the legal right of participation cannot guarantee their involvement.

What is difficult to ascertain from the consultation document is the level of participation expected or anticipated by enshrining rights and responsibilities within a legal framework. Paragraph 47 states:

*"... all patients will have the right to understand the options open to them and participate as fully as possible in decisions about their care and treatment."*

This seems to suggest that without the "right" enshrined in a legal framework, patients would be without an ability to understand. Such ability cannot be provided by a legal right, but is achieved by conditions which exist outside the legal system.

Paragraph 47 goes on to state:

*"Their views will be given the same level of consideration as clinical opinion when coming to decisions about their care and treatment."*

This is a worthy sentiment and no doubt in many cases suitable. Nevertheless the SWC question whether this is always appropriate or conducive to an improved level of care. It should be accepted that there are people within society who, for a variety of reasons, may feel threatened by this statement and their inability to live up to the expectations it raises.

Others may feel insecure owing to a perceived lack of ability in their practitioner and there would be a resulting lack of confidence about their care. The SWC believe that there will be people who feel patronised by being asked to make informed decisions about treatment.

Health care specialists, for example doctors and nurses, have undergone extensive education and training to enable them to deliver a high level of clinical opinion and informed advice. Patients attempting to contribute their views on a par with this could become frustrated or embarrassed and this may result in relationship tensions and delays to treatment which will not, in fact, enhance the patient's care progress.

Equally, by protecting in statute the right of patients to participate and express their views during treatment the message may be sent to an overwhelmingly dedicated and skilled workforce that the Government do not have faith in the abilities either to diagnose or treat their patients with respect and consideration.

This seems at odds with the Government message:

*“For staff, the key issues were about feeling valued and there was a strong sense that we seemed to be moving in the right direction”<sup>4</sup>*

It would be disappointing for the workforce of the NHS in Scotland if that move in the right direction was diminished by a lack of rigorous evaluation as to whether every patient right, many already supported by the NHS Patients Charter and current law, would be improved by being placed under statutory force.

The importance of collective participation is also an issue highlighted to the SWC in our consultations with women across Scotland. We therefore welcome the Scottish Government's recognition that the health service is more effective when the people and communities they serve are involved in their design, development and delivery (Paragraph 48).

Women, in rural areas particularly, expressed the view that decisions imposed by Health Boards centrally do not always represent the most appropriate focus for their communities and they would welcome the opportunity to participate and have access to more devolved local strategies.

The SWC look forward to seeing Local Health Partnerships and communities benefiting from being provided with more opportunity for participation in developing their own health strategy focused on local health priorities.

Paragraph 57 states that patients will have a right to information about how well the NHS in Scotland is being run. The SWC support the principal of:

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<sup>4</sup> From forward statement by Nicola Sturgeon Cabinet Secretary for Health and Wellbeing – Better Health ,Better Care: Action Plan Scottish Government 2007

*“...an NHS where ownership and accountability is shared with the Scottish people and with the staff of the NHS.”<sup>5</sup>*

We therefore support the right of patients to information about how well the NHSS is performing. However the SWC find it difficult to extend that support to the proposal this information will be supplied to every household in Scotland by the distribution of an Ownership Report. Given the existing health inequalities which still exist in Scotland and the budget constraints that limit numerous areas of care provision a cost/benefit analysis must be undertaken and the co-owners of the NHSS - the people of Scotland, consulted on whether they agree this is the best use of their money.

### **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
- § 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?

### **SWC Response**

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<sup>5</sup> Better Health, Better Care Action Plan, The Scottish Government 2007, section 1.1., page 5

Rights to privacy and confidentiality are pivotal in supporting many aspects of care. Among other things they can increase patient confidence, provide assurances that allow successful communication and support the delivery of other patient rights such as respect and dignity.

The SWC believe women will welcome the consultation paper's assurances on the standard of facilities and the appropriateness of the environment in which patient treatment and examinations take place.

As the consultation paper outlines in Paragraph 54 a comprehensive number of legal rights attach to the Data Protection Act and offer legal protection to individuals in regard to the accessibility, confidentiality and relevance of information held about them.

The same act requires the holder of this information to process and store it securely.

In light of the protections already afforded by the above legislation the SWC would welcome further clarity on what, if anything will be enhanced by this proposed legislation? In respect of rights pertaining to the retention, processing and access to their private details will these proposed rights empower patients further?

#### **QUESTION 8: Right to Independent Support & 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
- § 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 & Redress?

What do patients and/or the NHS need to do to make this happen?

### **SWC Response**

The National Party manifesto contained a commitment to introduce a bill intended to:

“replace the current NHS clinical negligence scheme with a no-fault system of compensation”

The consultation document considers the people of Scotland not only customers of the NHSS but also mutual owners of the services. For this reason the advantages or disadvantages of the manifesto commitments with regard to a new system of redress are worthy of serious and wide ranging consultation and debate.

The SWC are therefore concerned that the right of redress is only briefly alluded to on paragraphs 68 and 69 of the consultation document.

Paragraph 68 points out:

*“Evidence is that in most cases what people are looking for when they seek redress is an explanation or and apology and an assurance that lessons have been learned,...”*

The SWC would concur with this position and believe many complaints would be appropriately and satisfactorily resolved by this approach therefore it is essential that patients feel confident that raising issues will not result in retribution.

Women who attend SWC events have frequently alluded to the difficulties of resolving complaints or being able to address issues at this level of dissatisfaction. Being ill or in need of support due to health issues exposes vulnerability in patients which can be exploited at all sorts of levels. The SWC believe that dispute resolution between patients and providers would be greatly enhanced by genuine efforts to improve avenues of redress for patients below levels where proposed financial redress might be appropriate.

The SWC therefore acknowledges that suggested expansions to the current Advice and Support Services and the creation of independent Patients’ Rights Officers may assist in that outcome.

The SWC do not presume to have insight into the legal nuances of seeking financial compensation or assessing at what level that compensation would be appropriate recompense nor can we attest to the possible financial implications to either patients or the NHSS of a no-fault compensation scheme.

It is noted by the SWC the Scottish Government favour a no-fault compensation nonetheless the Government also comments in the consultation document that there is need for further work on the practical implications and potential costs of a change in compensation arrangements.

The SWC would strongly recommend that “further work” is carried forward a separate exercise supported by additional consultation and input from a specialist reference group which include members of the public and legal profession.

We believe that without a robust financial memorandum supporting any proposals with regard to a no-fault compensation scheme it is impossible to contribute a more meaningful response to this question.

The SWC consider the proposal on Redress too vague to measure or support.

The expectations of a compensation culture can have a negative impact on realistic and achievable levels of care or treatment and implementing this as a means of financial redress must be carefully considered and its value measured against what can presently be pursued through the Public Service Ombudsman and the courts.

We would urge the Scottish Government to fully assess the practical, legal and financial implications of a no claim system of compensation more especially the impact this would have on drawing much needed money from front line services.

The people of Scotland as co-owners of the NHSS and also as potential pursuers of financial redress need to be entirely sure that the avenues are fair and equitable for all protagonists.

In conclusion the SWC are of the belief that most patients do offer feedback in a positive and constructive way and while we certainly acknowledge that it is unacceptable if it is not conducted in this manner we suggest that the mutual responsibilities of respect and dignity already underline this point.

The SWC believe it would be reasonable to state that when ill, in pain, or suffering mental health problems, complaints may be delivered in a manner which might be less than positive or constructive.

There is a possibility that underlining patient responsibility (as outlined in Q8) to feed back in a constructive and positive way will actually further inhibit patients in expressing dissatisfaction when they are in a vulnerable situation.

If you require further information or copies of this report please contact Isabelle Lannon, SWC Policy Officer on 0141 248 8186 or email [isabelle.lannon@scottishwomensconvention.org](mailto:isabelle.lannon@scottishwomensconvention.org)





Scottish Women's Convention  
Blythwood House  
200 West Regent Street  
Glasgow G2 4DG  
0141 248 8186

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