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

About Action for Sick Children Scotland

Action for Sick Children (Scotland) has for more than thirty years campaigned for children and young people to receive the highest standard and quality of care when they are ill in hospital, at home or in the community. Whilst our core purpose remains that of influencing and collaborating to secure best health care outcomes for sick children and young people, our activities also reflect the dynamic developments in the planning and delivery of health care in Scotland today. We work in partnership with parents, carers, health care professionals and most importantly with children and young people themselves.

Action for Sick Children (Scotland) (ASC(S)) is a member of the European Association for Children in Hospital (EACH). A key focus for members is the EACH Charter and its ten Articles which explain the rights of children, young people and families when using health care services. The EACH Charter is underpinned by the United Nations Convention on the Rights of the Child and members aim to have the principles of the Charter incorporated into their countries' health laws, regulations and guidelines. We are delighted that the Scottish Government has recommended in ***Delivering a Healthy Future: An Action Framework for Children and Young Peoples' Health in Scotland***, that the EACH Charter is to be used by NHS Boards as a standard against which to assess their child health services.

ASC(S) works in partnership with parents, carers, professionals and the children and young people to access best quality healthcare provision. We do this by collaborating at both national and local level on government policy and steering groups and locally and regionally through health boards and regional planning groups. Our staff around the country work closely with families, children and young people as our current children and young people's health rights project demonstrates, with its accompanying resource pack and DVD developed by children and young people themselves.

General

Action for Sick Children (Scotland) warmly welcomes the introduction of a Patients' Rights Bill for users of the NHS in Scotland and is particularly encouraged that right from the start this has not been presented as a one-way street by any means but that patients are required and should expect to play their part too in taking some responsibility for their healthcare management in order for the patient-professional partnership to proceed in the patient's best interests. The professional is the medical expert and the patient is the expert on themselves as an individual.

We are staunch supporters of the philosophy of self-management for patients affected by Long Term Conditions (LTCs) and believe that with appropriate supports and strategies in place, people can be helped to better manage their condition with better outcomes for themselves and their families. We are currently developing a generic self-management programme for young people with long term chronic conditions including those moving from paediatric to adult healthcare and we are sure this Patients' Rights Bill will be fundamental to this overall process.

We are delighted to see the First Minster's statement

I want you to know that your NHS will help you to access your rights………………………

as we have just recently developed a Children and Young People's (CYP) Healthcare Rights Resource Pack which is designed to enable people working with CYP to help them understand the nature of healthcare services open to them, how to access these and their rights in relation to their use. It seems that this is in perfect synchronization with patients rights as outlined in this Bill and should enable young people to make the best possible use of healthcare services.

ASC(S) does, however, have one major reservation to the Bill as it stands and that is its total lack of specific mention of children and young people. We understand that the Scottish Government may take the view that the bill covers all ages from the cradle to the grave but strongly recommend the specific inclusion of CYP as a separate group. They are different in so many ways that it is simply not possible to treat them as mini adults. They are growing and developing through all the stages from babyhood on the way to becoming an adult. They have education needs which adults do not or which are voluntary. The Law as it pertains to rights is different for children. They have a distinct health service and in addition have to negotiate the difficulties of transfer from paediatric to adult services. Their treatment and rights in relation to this, of necessity, involves other people - their parents, carers and families. They cannot be treated in isolation as if these others did not exist. Thus we strongly contend that they should have a ***separate*** Bill of Rights but that if it is to be part of a universal bill then for all the reasons above, there should, at the very least, be separate mention made of where the rights differ.

We would like to draw the team's attention to paragraph 2 page 1 which explains the EACH Charter and its 10 standards for children and young people's healthcare. No discussion of CYP health rights can be complete without reference to this document.

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?

Action for Sick Children (Scotland) (ASC(S) welcomes the Government's commitment to the 12 week waiting time but would caution that this is not promoted and adhered to at the expense of other services and as we make clear below there is not a slavish following of this regardless of individual need.

Children and young people distinction: We are concerned that throughout this document there is no specific mention made of children and young people as individuals with very specific and distinct needs from adults. We would like to see a more explicit description of the rights of Children and Young People with regard to access. Para 22 states that ***access to health care must be equitable……including age***…

Children and Young people (CYP) do need special support to access health care through the presence of a parent or person close to them. In this regard we would draw the Scottish Government 's attention to the EACH Charter, Article 2 which states

…***the right to have their parent or parent substitute with them at all times***.

It then goes without saying that appropriate accommodation will need to be available for the carer accompanying the child and again we direct readers to Article 3,

Accommodation should be offered to all parents and they should be helped and encouraged to stay……

Para 22 - We would urge the government to take account of the importance of providing age appropriate care services especially for young people. This right of access needs to be kept clearly in mind in health care settings which are not specialist child or adolescent centres such as District General Hospitals.

Para 24 - Economics and Geography: There can be no discussion of the right to accessible and timely health services without also considering Scotland's economic and geographical setting and the implications of this on those families who have to relocate to access not only the best possible health care but any health care at all, depending on where they live in relation to the service provider.

ASC(S) was involved in the ***2 Dear to Visit*** campaign with Contact a Family and while families are now able to claim costs retrospectively, travel costs to specialist centres are not re-imbursed to families who are not receiving benefits thus disadvantaging those families on low incomes perhaps just above the level at which benefits are paid One way to change this would be to institute a blanket payment for distance travelled to all children requiring specialist care (such as is used in Western Australia).

Para 22 - Education and staff training: There needs to be very wide engagement with health care providers in the adult sector to raise their awareness of the needs of CYP through the provision of training, in order that CYP have equitable access. ASC(S) regularly responds to families where the child or young person they are caring for is being looked after in an adult healthcare setting where little or no account has been taken of their age and stage and needs.

ASC(S) recommends that the team take account of the EACH Charter Article 8 which states that,

Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.

Paras 17-19 - Waiting times There should be a clear understanding of the aim of referral and agreed contract that involves both parties but the patient should have a say in what waiting time is acceptable. -In some cases the patient may prefer a longer time scale or it may be clinically more appropriate that a longer wait is agreed without the system indicating poor efficiency.

Para 19 - Any such promise of maximum waiting time should acknowledge the clinical priority of any major incidents, epidemics etc which may occur.

Information sharing and confirmation of understanding should be specified, in particular the realistic time allocation for explanation and negotiation. If patients are to be offered an open ended time scale for discussion and negotiation then the relevant health professionals should have this demand reflected in their job remit and taken into account in their time management. It is relevant to consider the practicalities of the increased time demand for relatives who regard themselves as having the right to be involved in decisions about an individual such as a child or adult with learning difficulty. When such relatives demand separate interviews and information sharing sessions, the time demand on the health care team can become excessive. Agreed standards for adequate allocated time and prioritisation for communication might address these issues.

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?

(ASC(S) is in full agreement with the inclusion of these entitlements and responsibilities.

We would add however that the section on respect needs to highlight the special challenges that come with treating CYP. In order to offer best practice in dignity and respect for CYP who are treated in adult hospitals and other health care settings, there needs to be better awareness of their needs and how to deal with them. The NHS needs to conduct widespread training needs analysis and subsequently offer appropriate training to staff and/or employ staff who are qualified in paediatric care. The ***right to be a child*** and issues around child protection are special considerations that need to be specifically mentioned and focused on in this section.

We would like to draw the team's attention to Article 10 of the EACH Charter which is relevant to Question 2 – the right to respect.

Children shall be treated with tact and understanding and their privacy shall be respected at all times.

It is also worthwhile commenting on the fact that children and young people should be given the right of personal retreat, to be alone and to have private communication with staff. This may appear to be stating the obvious but we are reliably informed that it does not always happen. ASC(S) has encountered an example of this when two young patients (aged 9 and 11) on a visit to an outpatient department felt they were criticised for not wanting to talk to the entire care team all at once (during a review of care). Both children felt it would have been better to talk to one member of the team they liked.

Para 28 - As previously noted, the question of age appropriate care settings becomes very important when considering the right of respect. In some District General Hospitals for example, ENT surgery and aftercare is carried out in an adult ward setting. Although children are separated physically from the adults, there are still adult patients wandering about the ward. We do not feel that this is an example of best practice of a child's right to ***care that is responsive to the individual circumstances of their life, such as their age, disability, gender, race, faith or belief, or sexual orientation*** (para 28)

Of equal importance to the dignity and respect of the patient is that of staff members' and patients' responsibility in this regard. Current emphasis on staff rights to be protected from abuse, bullying and harassment are all helpful.

This will become even more important when the age of admittance to paediatric services rises and staff find themselves treating/caring for older teenagers up to 16 and perhaps beyond.

The next two paragraphs contain specific points in response to *What do patients and/or the NHS need to do to make this happen?*Training staff in coping with violence and aggression and any form of discrimination towards staff with available counselling when such behaviour is experienced is helpful. This training should start from students onwards and should include permission to walk away from a sick patient who poses a threat to staff safety.

In addition, there is a need to clarify what penalties apply for those who behave inappropriately towards staff - either by removing the right to being seen promptly, being expected to contribute to the cost of the additional resources required to cope with violent or aggressive patient care etc. Community service to improve the environment around health facilities might offer an appropriate penalty in some cases.

Along with rights come responsibilities and it is important that in any patients' rights bill, the user is clear that they too have certain responsibilities and only by respecting these in a reciprocal way, can they benefit from the true patient professional partnership working in their best interests.

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?

ASC(S) welcomes the proposals outlined under question 3 and is in broad agreement with the points made but we would like to make certain comments.

Para 34 - For care to be truly ***safe and effective***, children and young people under 16 should ***not*** be admitted to adult units/wards. Para 29 and 34 (first bullet point) make clear the necessity for healthcare professionals to have the right training and skills for their job. We would again draw the team's attention to the EACH Charter Article 8 (see above) which underpins this very important area. As services become more and more centralised and specialists also centralise in line with this reconfiguration, it will become increasingly difficult to deliver treatment to children and young people within local (see also Childhood General Surgery, National Delivery Plan for Children and Young People's Specialist Services, Scottish Government 2008 in **Para 31** - Children's health and safety regulations in all waiting areas of outpatient and A&E units are not being adhered to in all places in Scotland. Children should have separate or exclusive use of waiting areas and a member of staff should be responsible for supplying suitable reading materials and toys to those areas.

ASC(S) welcomes all the points made at Para 34 but would suggest that there needs to be further explanation of the terms ***effective care*** and ***continuity of care***. Here it needs to be made clear that for care to be continuous, inter-agency work needs to be encouraged and improved in order to then make care effective. This is just as important in the case of CYP with complex healthcare needs as it is in the care of the elderly or indeed palliative care for all ages. (See Article 9 of EACH)

Continuity of care should be ensured by the team caring for children

Para 32 and 30 - We suggest that agreement about what independent advice is envisaged and how this will contribute to the current Patient Safety Alliance without detracting from essential health care resources would be helpful. If this role is expected to be through the third sector then formal agreement and appropriate resources should be offered to ensure equity of provision across all areas.

Para 33 – ASC(S) welcomes and is in full agreement with these proposals for patients to take on the role and responsibility for their own care and note the issues of adherence and compliance which form a fundamental part of the self-management strategy for living with a LongTerm Conditions. Patients could also be asked to have responsibility to identify what additional measures they think would improve their safety or in what way following advice about treatment may be difficult for them so that the health care team can target their efforts effectively.

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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 another health care team or provider, with regard to confidentiality, wherever possible;
- translation or interpreting services;
- independent advice and support, or to an advocate or other supporter; and
- to ask questions [14] 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?

The EACH Charter details the importance of children and young people being included in discussion about their health and care. All communication should be child/young people friendly, clear and appropriate to age and level of understanding. ***Children and parents shall have the right to be informed in a manner appropriate to age and understanding*** Article Information about specific health procedures should be given by a member of staff trained for the purpose (such as a paediatrician, children’s nurse, hospital play specialist).

We agree with the points made but feel that the needs of CYP must be highlighted specifically, as there are specific challenges in communicating with younger children, teenagers and their families. The Bill does not go far enough in explaining that CYP have different communication needs, that teenagers respond differently from adults and that they cannot be treated like “mini adults”. There is not enough expertise outside paediatric settings to ensure age-appropriate communication. We recommend therefore that this be mentioned in a separate paragraph. (See Articles 4, 5 and 8 of the EACH Charter, quoted elsewhere)

There is often more than one person involved when communicating with CYP and the lines between consent, confidentiality and the sharing of information are less distinct than when dealing with one consenting adult.

We welcome the specific mention in Para 36 of the critical importance of good communication with patients when things are changing and in line with this would like to see specific mention made of the classic *transition* period for YP.

Not only do CYP have different communication needs from their adult counterparts necessitating different communication skills, but as adolescents they straddle two very different systems as they navigate from paediatric services to adult services commonly known as ***transition***. We strongly recommend something specifically written into the Bill which states that communication must be maintained before, during and after the transition period from paediatric to adult services. ASC(S) has had experience of two young people with long term conditions (diabetes) who said the hand over was very badly- handled, causing them distress and anxiety at a time when they were also having to cope with a new school and other personal changes. The problems stemmed primarily from a lack of involvement on the part of adult physicians in the handover of care. The young people concerned were not told who their named nurse would be or how long they would wait for appointments. Article 9 of EACH Charter makes this very clear:

Continuity of care should be ensured by the team caring for children

Para 38 - We have a long history and considerable experience of providing information, advice and support to families when their child is sick and we have found that it is rarely sufficient to give the information once or in only one format but that this needs to be repeated several times or at least understanding checked out. Clearly it must be a two-way process with the onus also on the patient to communicate what he/she does not know or understand. The difficulty is that the patient often does not know what he/she does not know! – hence the risk of misunderstanding or lack of understanding.

Para 38 - The identifying of every health care worker involved in care is unlikely to be realistic or helpful. It would be better to offer every patient the right to ask the person's name and role if this is not offered on introduction.

We are very encouraged to see the recommendation of one identified supporter for detailed communication who will identify the independent advisor to ensure all patients have equally effective support.

Whatever title they have, it is vitally important around the time of transition for each YP to have a key worker or supporter – someone who has the skills and knowledge to co-ordinate the other professionals involved and provide an overview of the care the YP receives. This is particularly important when there are more than two services in addition to the core services e.g. GP, Health Visitor

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?

Information is empowering and handled appropriately can enable families to cope better in their caring role. It is however a two–edged sword and patients’ increasing use of the internet to find out about their condition or their child’s condition needs to be managed very carefully and handled with extreme sensitivity.

ASC(S) agrees with the rights to have information about services, treatment and care but we feel that although children are specifically mentioned in this section, the paper does not go far enough in stating that some patient groups might need specialist professional support to access and understand information. In the case of CYP this might be in the form of hospital play specialists, youth workers and/or literature specifically written to target their age group. We are very pleased to see the inclusion of …***other independent supporter***… (Para 42)

In addition to the information itself and services of a supporter, we would like the bill to include some mention of the fact that these patients also have the right to be given time to understand and absorb the information. Targets and short appointment time allocations could severely hinder this process for CYP. (See Articles 4 and 5 of the EACH Charter)

Para 40 – ASC(S) welcomes the commitment to provide information to those who have additional needs in terms of understanding information but recommends that the document specifies ***what*** options are offered for means of communication and how the NHS will ensure these are universally available at point of need.

Parents should have the right to know that those caring for their child are trained to the appropriate level as laid down in the the EACH Charter and the UNCRC both in Primary and Secondary care.

Any change in the role of health professionals or any changes in service delivery in locality should be communicated to patients and local service providers.

Para 44 – we note with interest the introduction of a National Health Information and Support Service but question whether with the plethora of existing portals and information services, this might prove to be duplication. Specifically we wonder how this will differ from existing services such as NHS24 and Independent Advocacy and Support Service. Would it not make more sense to expand the services we have rather than set up yet another one?

Para 45 – We would like to register our concern about the statement on patients having the right to have copies of letter, faxes, emails which relate to them. The need for care should be highlighted particularly with reference to email as there are issues of internet safety and security. NHS Boards will need to have robust procedures in place before emails are shared outwith the protected internal NHS internet structures. ASC(S) knows that some NHS Boards are now looking at this issue but some clarity around this statement would be welcome.

There is also a difficulty with the issue of confidentiality when sharing information with children. Does the child see the letter etc or is it only to be read by the parent/guardian? Who makes this decision and based on what? This whole area will require greater clarity and can perhaps be included in the Code of Practice or Guidance which we assume will accompany the completed legislation. This can present a legal minefield as it is usually down to a doctor's judgement about the capacity of a child/young person either to consent or to ask for confidentiality, and this is why we feel it needs to be mentioned in some format within the Bill.

The age at which information should be shared also needs to be discussed in some part of either the legislation itself or the Code of Practice.

A very important part of the right to information is the education of children and young people with respect to their rights and responsibilities, in particular the promotion of EACH Charter could be mentioned. It is not just information about the services and treatment/care options.

Para 45 – Information about their rights will empower the patient to play a fuller part in their care. Another area where this could be made more fair and equitable, is for all families requiring specialist care to receive information and support (family support worker/key worker/social worker) in applying for all benefits available to them (such as carer’s allowance).

It is worth mentioning the following example: when we once asked managers of Outpatient Departments to display the EACH charter in the waiting area, their worried response was that ***patients might start to demand their rights or insist on services which were not being met or delivered!!!!!***.

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 agree with all the rights in regard to involvement and decision making. In order to achieve this, more investment needs to be made available to support CYP and their families. Scots Law states that anyone – regardless of age can give or refuse consent to treatment, as long as they can understand the issues. In order to empower CYP to practice this right, they need to be supported through play and other age appropriate services. At the moment this can sometimes be achieved in paediatric settings but is very difficult to access in adult settings because of lack of paediatric nurses, clinicians and AHPs. Psychological services and pain teams need to be more widely available. (See Articles 4,5,7,and 8 of the EACH Charter)

We propose that the Code of Practice makes mention of the use of voluntary organisations who represent children, young people and their families as one way of encouraging participation. These groups often have a broad membership and access to families as users of the NHS and can very often act as brokers to bring families and professionals together.

Para 50 - NHS Boards will have to look at the mechanisms currently used to involve and encourage participation of children and young people. At present their provision is inadequate with many participation groups meeting during the day and with agendae which can be very off putting for a young person. One example we can give is of a young girl in Ayrshire who wanted to work with PPF but after one meeting, where the only thing discussed was incontinence issues and care of the elderly, she did not feel appreciated or involved. Her answer was for the PPF to include young people on the agenda at specific times and let them know that beforehand. Tell a young person if meeting is going to be about elderly services and give them the option to attend, rather than assume everyone wants to be involved in every NHS decision about every patient group.

In order to develop better/improved involvement of children and young people, go to where they are and discuss health care, such as PSE classes in school: focus on more than just drugs, sex and alcohol. Discuss health and well-being in a broad sense and health rights. Provide better funding for use of leisure facilities by all, not just those who can afford it. Provide better support for sport in school for both girls and boys.

As long as arrangements for the inclusion of children and young people are made as outlined under Question 5, above then we welcome the proposals for participation. It would help the NHS if the education curriculum included relevant learning opportunities for children and young people in analysing health information and making decisions about their own health needs and care.

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?

ASC(S) agrees fully with all the statements, however we know that parents have concerns about the amount of information that is available about their children and who has access to it. Too many times we have seen people access private information when they should not have and this lessens their trust. A robust system of privacy protection needs to be in place, and needs to be properly funded.

Para 57 - It is essential that all health care facilities are designed and used in ways that facilitate confidentiality and privacy and that where this is not realistic the health professional is supported in their efforts to make realistic compromises. Open plan health facilities may pose a risk to confidentiality while improving other aspects of efficiency of health care and should be avoided. Office accommodation, the position of telephones etc may all be relevant in this regard

Para 58 – In order for patients to enjoy the right to privacy, inter-agency work needs to be soundly supported and furthered by sound IT systems and robust mechanisms to insure privacy. GIRFEC needs to be incorporated here and excellent child protection procedures must be in place – without jeopardising privacy rights. (See Articles 9 and 10 of the EACH Charter)

Para 58 – More attention needs to be paid to the CYP's right to confidentiality. For adults, there is an automatic presumption to confidentiality and yet youngpeople are ironically not benefiting from this, as very often professionals do not respect their right.

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?

Para 71 (first three points) – We agree with the inclusion of rights and responsibilities and would add that there should be special provision for children and young people when they wish to feedback or complain about their care. Such actions should be made possible independently from their parents if they so wish. Children and young people should be offered independent support that is specific for their needs.

Para 66 – We agree with the right to Independent Support and Redress. It is a positive step to say the Board should be pro-active in supporting patients to achieve this. However , the Bill needs to explicitly explain that CYP are facing barriers to access these rights because of their age and/or inexperience or lack of knowledge about these rights. They also need very specialised support to access independent advice services. There are currently not enough independent advocacy programmes for CYP available. Organisations in the voluntary sector should be enabled to access funding to offer this kind of support for CYP. (See Articles 4, 5 and 7 of EACH)

We would specifically mention ***children and young people*** in section 61 (the final sentence which talks about barriers facing particular groups). Some young people and children we have talked to over the last year did not feel they could complain as they felt no one would listen to them. So we would suggest the Bill mentions that support is required to enable children and young people to access the right of redress.

Para 66 - As far as independent support and advice services are concerned, we recommend emphasising the word ***independent***. The use of the voluntary sector (with appropriate funding from NHS Boards) to provide such services could be promoted and this would be especially relevant for those voluntary agencies who work only with sick and disabled children!

We support the current practice where the NHS works with existing partners in the voluntary sector to do this. We would draw the team's attention to the HRIS documents for under 16s which are very good, clear and to the point about ***consent/confidentiality*** and ***how to have your say***. We would warmly suggest that such good work continues to be funded.

Para 69 – We agree that the NHS complaints system needs to be simplified. Staff need to have reassurance that it is not a blame culture and patients need to see the results of complaining. Have lessons been learnt? If so, these could be publicised as examples of good practice.

The right to access independent advocacy should be mentioned as this can be the way some patients can be enabled to raise a complaint.

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?

We would like to take this opportunity to recommend that all ten of the EACH charter points are included in the Patients Rights Bill. We have mentioned Articles 4-10 which in any case have already been included in the Bill albeit without specific mention to CYP.

This means that the only two not mentioned in the bill relate to CYP having the right to have a relevant person accompany them and the provision of accommodation for that person.

ASC(S) knows of instances where, when the child has been accommodated in an adult ward, they have been refused access to their parents and the parents have not been kept informed about the course of the child's treatment. We are not suggesting that there is any deliberate intention to harm but simply that staff were working in an adult treatment mindset and should have been alert to the different needs and status of CYP.

Right to play education, and recreation– We would like to see specific mention of the right to education, play and recreation for children and young people when in hospital. The right to education, play and recreation of CYP who are ill has been missed out of the Bill. Sick CYP should not suffer educationally or socially because of their illness. Falling behind with their learning or losing out socially can lead to social exclusion and to emotional and mental health problems. The right to education is fundamentally important and is stated clearly in article 28 of the UN Convention of the Rights of the Child. Article 7 of EACH describes this right for sick CYP.

Children shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.

Currently there are very alarming differences in the provision of education for sick CYP. This often depends on which local authority is responsible for the education provision of a young person. The government should organise the education of sick CYP through the Department of Health and make it equitable for all sick CYP across Scotland.

End of life planning - Patients of all ages should be encouraged to consider how they would wish to be cared for in life-threatening situations, even if this is not immediately relevant to them. The current ***living will*** or ***do not resuscitate*** orders are all focussed at the time of crisis yet any patients wish to be assured they have been offered a view on their end of life care at time when they can think logically and are not feeling under pressure. The more this is made a routine consideration the less stressful it is likely to become for both patients, carers and health care providers and the less the risk of next of kin making inappropriate decisions on a patient's behalf.

Action for Sick Children (Scotland)

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