Irish Patients' Association

Pact for Patient Safety

February 20th 2018

Submission by Irish Patients Association

**Background: -**

The Irish Patients' Association is proud that we were the first independent cross disease patient advocacy group to nationally offer free support to patients and or their family's carers who had or are experiencing difficulties with the system. In addition, we also offer support to other disease groups in developing their own advocacy skills, or indeed that they may be compromised if they speak out publicly on certain issues, our strategy is to work in a mutually respected partnership with our engagement with all stakeholders, keeping the patient at the centre of all decision making. The underlying principles of patient Centered care to which we are committed as members of the International Alliance of Patients Organisation's ( A global patient advocacy body ) are:

Respect and support for individual wants preferences values needs and rights
Access to health care services warranted by their condition
Information that is appropriate, relevant and timely
Empowerment / motivation of patients to take responsibility for their health care and be independent as possible and for patient's organization to be recognized involved and encouraged to take a leadership role
Involvement of patients and patient representatives in all decision-making processes which will have an impact on patients' lives

# Legislative and legal issues

We don't speak on behalf of all patients but we do advocate based on those patients or families who have shared their experiences with us. Based on our extensive engagement with patients we summarise their 4 domains of risks as follows

1) Clinical
2) Medication
3) Management
4) Inequity of Access ( This also includes the determinants of health eg Housing, Education etc)

The language of patient advocacy both nationally and internationally is using the language of Rights more and more. This is because the violation of such rights may be upheld in national or through international agreements. ( Eg EU COJ ruling on cross border access to care http://europa.eu/rapid/press-release_MEMO-13-918_en.htm)

Stephen MCMAHON was the Irish Patients Association representative in the drafting of the European Charter of Patients' Rights and its signatory on behalf of the Irish Patient's Association. For the past number of years this charter has been celebrated by civil society and other stakeholders at the European Parliament – in the coming years we hope it will be marked in every member state.

Following an open tender DCU were awarded the project to independently academically evaluate these rights as to where they stood in Irish Law (report enclosed for your perusal)

In summary Equity of Access is listed as a social and economic right and therefor the rights bearers are Tax Payers. When we launched our report the political thinking at the time was there would be no more taxes to fund this principle. We would support such a constitutional entitlement of equity of access. Regardless of your considerations this does highlight the importance of enlisting within our society the support for additional investment.

The following are the EU Charter of rights

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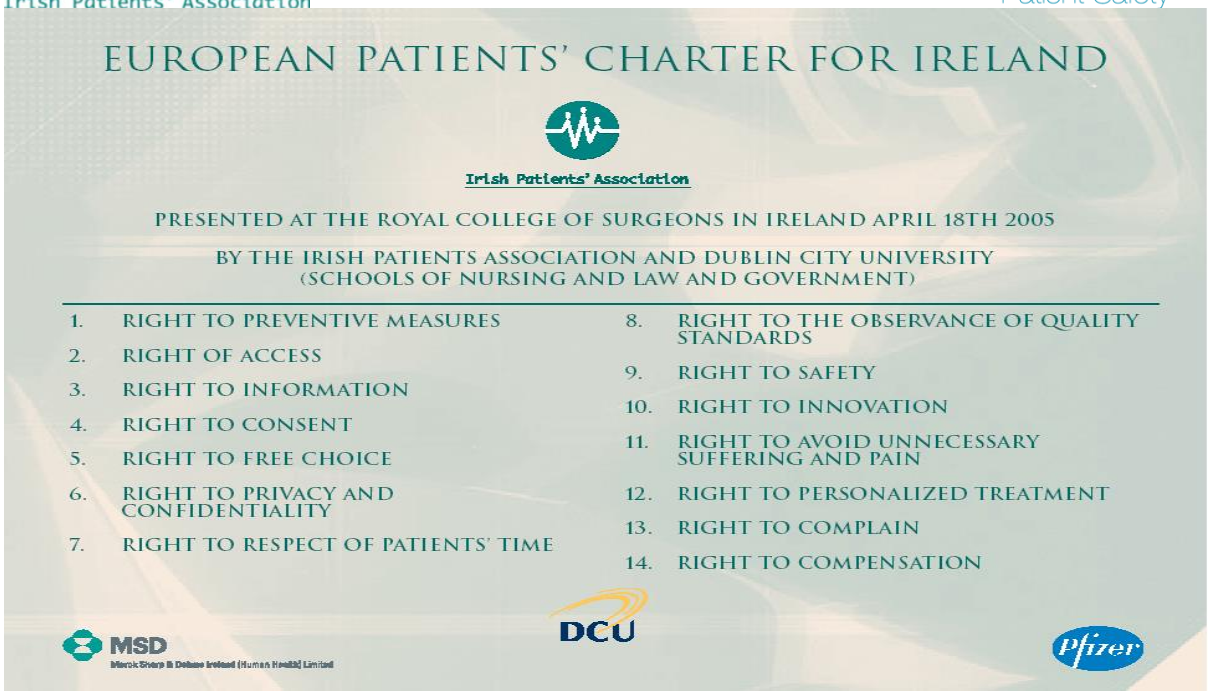


For your convenience, the DCU study groups these rights into 5 themes which are related and interrelated. Eg

**Theme A Access to Health**

Right to Preventative Measurers
Right of Access
Right to Free Choice
Right for respect of patient's time
Right to Innovation
Right to personalised treatment

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# Eligibility, access and equity

Today nearly 2.1 million people have private health insurance and have little or no waiting times for access to their consultant or treatment, of the remaining 2.5 million of people who do not have private health insurance almost 1 in 4 of them are waiting on some waiting list or other to have a consultant led appointment or planned treatment.

Simply put this is UNACCEPTABLE and every time they are put out or given undeliverable future dates for appointments or treatment's their rights to timely safe access to health care are being violated.

In a recent Consumer Heath Powerhouse 2017 Index, an established performance indication from the patient's perspective of Health Care systems in 27 EU member states it says ( full report attached ). This years report got little if any media attention.

"24th place, 630 points. Down from 21st place in 2016. Ireland drops in the Index for two main reasons: In 2017, Ireland is alone in last position for Accessibility, with patient organisations steadily giving very pessimistic feedback in the HCP survey. Unfortunately, this was confirmed by the Irish HSE and MoH after the release of the EHCI 2015 report, when they said in a memo that the programme initiated to reduce healthcare waiting times in Ireland aims at a target of no more than 18 months' (!) wait for a specialist appointment. Even if and when that target is reached, it will still be the worst waiting time situation in Europe."

When we take our current targets that if we meet them will keep Ireland with the worst waiting time in Europe with Informed Irish sources who have told the Irish Patients Association, that if nothing is done our public hospital system as they are now will not be able to treat any planned surgery within a few years.

So something is urgently needed, we currently don't have equity of access, going forward we also need an honest assessment of how policy makers and politicians have consistently, got it so wrong at such a cost to; past , present, and future public patients.

The Republic of Ireland is made up of two bubbles, one with the ability to pay for private health insurance the value of which grows with every reality of the hardship of public patients awaiting access to health care made public.

However the one area of experience that they share, is when they visit an overcrowded Emergency Department ( soon to be rebranded Trauma Centre) where some have to endure inappropriate long waits for access to a bed on award with all the associated risks.

What is the best way forward from the patient's viewpoint?

## Current and Future funding proposals

All we are competent to comment on is that removing private practice from the public health care system will add approx. €600 million to the existing HSE Acute Hospital budget. How will this deficit be recovered? We owe some €100 Billion due to the national financial collapse , that has limited the "fiscal space" now we are to fund a €100 Billion noteworthy capital development plan which in turn add additional repayments.

We appear to be distracted by an ideological argument that only public owned services are superior to private delivery; see CHP Index reality check. A public patient is not that interested in the method of reimbursement for the service s they receive insofar as they get timely high quality appropriate access that is cost effective for the rights bearers ( Tax Payers)

Maybe the fiscal space can be widened by greater accountability for policy makers and other decision makers within the system?

## Recruitment and retention of personnel

There are many health professionals we know who say that if they were to do medicine, nursing etc they would not have had the entry points to get access to the schools.

We need to invest in really opening up the supply side of the equation for example does a young person need 500 points to study nursing? Or indeed almost 600 point to study medicine. Not really!

No doubt there are many initiatives to retain staff that the committee will receive.

Just 3 ideas may be worth exploring

1) As it can cost almost €200,000 to the Tax Payer to train a young doctor, not quite as much a nurse, there should be disincentives if they emigrate in excess of an agreed amount of time.
2) AI and Technological disruption in the Acute & Primary Care sector has not been factored into any savings.
3) As there is growing competition for staff in many European states and further afield, maybe we need to consider pooling our recourses in some areas thru the use of technology.

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# Practical approaches to removing private practise from public hospitals including timeframe and phasing

The driver must be patient safety and timely access to care and treatments.

The Revenue lost must be recovered immediately in the public system.

Someone may have private insurance but having attended an ED as an emergency may exercise their right as a tax payer to public treatment

There should be no dramatic shut down but rather a gradual process, transitioning to exclusively private.

Private facilities should be able to bid for public work if they are more effective in costs and matching outcomes.

Key to the success of any of these plans or proposals is societal acceptance and fiscal support thru additional taxes. Before the first transition is made clear transparent proposals and targets must be given that are accountable if not achieved.

The delivery of these operational goals need a small independent executive multi managerial delivery group, focussed on the prize of better access to health for everyone.

The stark reality of previous reforms has been Poor implementation which is the underlying causes of patient's deaths and injury, we can and must do better and very soon.

Thank you for your attention and consideration

Stephen McMahon

Patient Advocate