Irish Platform for Patients’ Organisations, Science and Industry

Public Consultation on the White Paper on Universal Health Insurance

May 2014
IPPOSI UHI Submission

Introduction

IPPOSI is a unique partnership of Patient Groups/Charities, Science and Industry on the island of Ireland. As a patient led partnership, the platform provides a structured way of facilitating interaction between the three key membership groups (patients' organisations, scientists and industry (and where possible with State Agencies) on policy, legislation and regulation around the development of new funding mechanisms, medicines, products, devices and diagnostics for unmet medical needs in Ireland.

The IPPOSI vision is one where state of the art innovations in health care are available at the earliest stages to patients in Ireland. We do this through:

- Expertise
- Dialogue
- Consensus building
- Networking

IPPOSI is not a lobbying organisation but via expertise, dialogue, consensus and networking we work to smooth the path in Ireland for new medicines and therapies to move from basic science in laboratories to the patients who need them. We hope that our unique patient led partnership base will bring an added-value perspective to the Department’s consultation process, which we are happy to participate in.

The IPPOSI leadership team and our member organisations welcome the opportunity to submit a response to the ‘White Paper on Universal Health Insurance’. We welcome the commitment to the great deal of reform that is envisaged, and the principles upon which the changes are based, and would most certainly welcome any improvement in service delivery that prioritises access based on need.

Our submission in response to the White Paper is based on the output from our own consultation process. In order to best represent our members views and concerns, we held a half-day information and consultation seminar based solely around the White Paper. The seminar was attended by over 50 leaders representing patients’ organisations, science and industry, who enjoyed an informative presentation and questions and answers session with Mr. Eugene Lennon, Principal Officer, Universal Health Insurance Department.
Our Thoughts

While we welcome the publication of the White Paper and the ongoing consultation process, there are a number of areas where a greater deal of thought, clarity and consultation are required. In our view, there are still a number of outstanding questions and issues that are as yet unresolved in relation to the introduction of UHI. In short, we cannot clearly envisage the end game at this point. Our members need a concrete vision of where the journey is leading us and what the citizen and patient benefits will be.

Any large-scale change process such as this should be based on the values that society hold, and we welcome the fact that this approach was reflected in the White Paper, having developed an indicative ‘values framework’ to stimulate collective deliberation and public debate. In saying this, it may have been beneficial to involve key stakeholders in the early development of the indicative values framework. Being presented with seven potential values may pre-set the agenda to a certain degree, preventing input and original thought from the people most affected by this change (For example the values seem heavily skewed towards economic and business perspectives rather than a patient focus). In saying that, we do appreciate that this is a work in progress and that the fundamental building blocks have indeed been laid out.

In general, we believe that the proposition needs a broader and deeper discussion because:

- Much of the detail is still unknown at this point, and it is unclear how Universal Health Insurance will work in practice, making it difficult to respond to in this consultation
- There is a degree of misconception in the public eye, with people confusing Universal Health Insurance and Universal Health Care
- We note that there is no firm commitment to improving the lives of people with rare diseases or chronic diseases
- Some of the language used in the White Paper is around business models and customers. One thought is to potentially make the rest of the consultation and engagement period more patient centered and jargon-free
- Our members question whether it is possible and affordable for access to be increased without spending substantially more than we are currently spending on our health system
- We need to understand how UHI will be regulated and how the patient/consumer will be protected – Will this be done by the National Consumer Agency? What role will HIQA have to play? A strong degree of review and oversight by a designated body will be crucial
• There should be more clarity around the patient level and system level benefits that will arise from Universal Health Insurance. A ‘Benefits statement’ could be provided in order to clarify and quantify this, in terms of: Access, cost, quality and other metric improvements

• There is a genuine fear amongst some patients and other stakeholders that once we go down this route we will end up with a US style system of healthcare, heavily privatised and commercially focussed

As well as the above, throughout our own consultation process we discovered that a number of common themes arose, which our members thought warranted further discussion and debate. We have outlined these below under a number of thematic headings.

**Patient Voice**

We firmly believe that the transition to and implementation of Universal Health Insurance should include engagement with, and be cognisant of all relevant stakeholders, in order to better understand and respond to the patient needs. To ensure that health policies are designed with the patient in the centre, key stakeholders including patients, provider groups, payers, pharmaceutical companies, academics, NGOs, not-for-profit organisations and policy makers should be engaged at all levels of decision-making in order to identify fundamental health care needs and guarantee that the services delivered reflect patient needs and expectations. With that in mind:

• A second round of consultations with a more fully developed concept and indicative basket of services would be beneficial

• There is a genuine fear amongst some patients and other stakeholders that once we go down this route we will end up with a US style system of healthcare, heavily privatised and commercially focussed

• Where will the patient voice be captured and represented during the transition to UHI?

• Our members require a greater level of clarity around where the Patient Safety Agency will sit, and the role it will play during the transition to UHI

**Access**

We welcome the commitment that there will be equal access to health services in future, based on need rather than ability to pay, and the commitment that the new system promotes equitable access to high quality care. Throughout our discussions with our membership, there were concerns that there may be access restrictions due to budget, resourcing, geographical location, and the final composition of the UHI basket of services. Some of the key points and questions that were raised, which will have implications for a number of patient groups are outlined below:
• Is it possible and affordable for access to be increased without spending substantially more than we are currently spending on our health system?
• Notwithstanding the good work that the Special Delivery Unit is carrying out, with the introduction of Universal Health Insurance and more equitable access, will average waiting times rise due to a surge in demand for services? Particularly if no additional funding is envisaged
• Our members would value a commitment that access to services and availability of medicines will be improved for the large cohort of patients with rare diseases
• The parallel move to Universal Primary Care may mean much heightened demand, leading to reduced access and availability of GP services
• How will access to services be affected by age profile? In the current system, a number of young adolescents fall out of the system between the ages of 16 and 18. We must ensure to improve this under UHI
• At present, access to some services and medicines is based on where patients are geographically located, how will the new system ensure equitable geographical access and require insurers to deliver it?
• The ability to obtain the insurance that you need and require could also be a potential access issue for a large number of patients
• The system needs to ensure continuity of insurance cover. Insurance ‘switching costs’ and ease of switching insurance provider needs to be analysed in advance and set out clearly
• In light of the problems patients are having with the cost of medication, it seems inequitable that they would continue to pay for filling prescriptions. This has the potential to hinder medicines adherence even more that at present.
• With the large cost of funding medicines reimbursement, this is an opportunity to build on the work of Professor Barry and the national medicines programme in enhancing safe and rational prescribing/reducing waste

Safeguards

As per the consultation document, there are indeed a number of questions and issues arising around the need for safeguards to be put in place with the move to a Universal Health Insurance System. Some of the issues and questions that our members raised are outlined below:

• A framework mechanism for developing safeguards should be developed from the outset
- There should be safeguards in place to ensure that insurance companies cannot ‘opt out’ of providing certain services if they are too costly
- We need to understand how UHI will be regulated and how the patient/consumer will be protected – Will this be done by the National Consumer Agency? What role will HIQA have to play? A strong degree of review and oversight by a designated body will be crucial
- Innovation and research & development are crucial to the progression of health services throughout the State. We need safeguards in place to ensure that innovation and R&D are protected and enhanced. How will the level of research output be improved and monitored under UHI?
- What safeguards can be put in place to ensure that the most vulnerable in society are protected with the appropriate level of cover?
- Safeguards need to be developed to ensure continuity of cover for people at high-risk of lapsing i.e. Those in lower socio-economic groups and certain age cohorts
- We need to effectively mitigate against a decline in quality standards, which could potentially arise due to heightened demand and reduced funding
- A data baseline, against which key performance metrics can be measured, should be developed. Without baseline data there is no way of measuring the success or failure of the system
- We need to ensure that international best practice is being used in the design of and woven into the UHI insurance policies
- Safeguards should be put in place to ensure that the Clinical Programme Guidelines are being implemented speedily and effectively throughout the transition to UHI
- The system needs to ensure that orphan drugs are being protected with ring-fenced funding
- How can we ensure the sophistication, capability, resourcing and skill mix of those charged with carrying out the assessment for the ‘basket’?
- We believe that a long-term view should be factored into the evaluation of benefits for inclusion under the scheme. This will also help to avoid an ‘annual contracting’ mentality

**Structural Issues**

A common theme throughout our own consultation process centered around structural issues. There is a great level of change ongoing in the health system at present, and questions arose as to whether all of the elements outlined in ‘Future Health’ could be addressed and implemented in such a short space of time. Some of the issues and concerns raised are outlined below:
• Questions from our membership base arose as to whether the multi-payer model is the most appropriate model in an Irish context, given the challenges of scale and competition, and discussed the option of having a single-payer model

• There is a view in IPPOSI that Not-for-Profit insurers should be eligible to participate

• A consensus emerged that there still seems to be a focus on interventions in the health system, as opposed to prevention and health promotion. It is critically important that this is improved within the new system, and that the Health and Wellbeing Directorate can progress this agenda through the implementation of ‘Healthy Ireland’ in a radically different health model

• The National Clinical Programmes are at different and varying stages of implementation. Our members feel that the move to UHI is an opportune time to reinvigorate the restructured programmes to ensure that best practice models of care are funded, resourced and implemented as speedily and appropriately as possible

• During the development and ongoing implementation of Hospital Groups, members question how much choice will patients have in terms of which hospitals they attend and which treatments they are entitled to in different hospitals under the basket of services. The concern being that certain hospitals will be more difficult or more expensive to access. Might a two-tier premium hospital/inexpensive hospital model emerge, with the access and quality implications that this entails?

• In general, does the health system as it currently stands have the capability and capacity to implement and cope with all of the required changes; UHI, Money Follows the Patient, National Clinical Programmes, Health and Wellbeing agenda, Hospital Groups, Universal GP care, new Directorate model?

• In the move to UHI, there is a heightened impetus and requirement for the Individual Health Identifier / Unique Health Identifier, in order to track and monitor progress and improve transparency and quality. IPPOSI members would welcome this move and over the last 5 years have produced many papers on the importance of electronic health information in the context of the Health Information Bill and the Health Identifier Bill

**Benefits Statement**

It became clear from discussions between our members and patient leaders that there is a dearth of understanding and awareness as to the actual benefits that will be realised in practical terms from the move to Universal Health Insurance:
There is ambiguity around the timeline to full UHI implementation
There should be more clarity around the patient level and system level benefits that will arise from Universal Health Insurance. A ‘Benefits statement’ could be provided in order to clarify and quantify this, in terms of; Access, cost, quality and other metric improvements
We believe that in designing the UHI system and basket of services within, there should be more of a focus and emphasis on the ‘outcomes’ that will be realised by patients at large, and society as a whole
There is a case at this stage for attempting to quantify the ‘Economic and Social benefits’ attached to keeping the population healthy and active in the workforce. Various studies have shown that there are productivity and economic gains, as well as reductions in social welfare costs from taking proactive steps to keep the population healthy, rather than using purely interventional methods to treat sick patients.

Resourcing

One of the overarching themes that came through from our members was that of resourcing. Although a great deal of work has been done to look at international models with a view to costing the UHI model, a number of questions remain:

- Fundamentally, in the current and projected economic climate, our members questioned whether the state can afford to move to a system of Universal Health Insurance, considering that some international models have shown that healthcare costs have risen substantially with the introduction of UHI
- There was concern that the system could lead to putting basic healthcare beyond the reach of individuals due to budgetary constraints and restrictions
- International models have shown that under UHI, there is still a high proportion of individuals that purchase supplementary voluntary private health insurance:
  - The Netherlands - 91%
  - France - 92%
  - Israel - 80%
- The above evidence could point to the possibility of a reversion back to a two-tier system where those that can afford supplementary health insurance have greater access to a wider range of services
- As indicated at the outset, it has been stated at Government level that the health system will not cost any more than it currently costs. While IPPOSI and our members are aware of current fiscal constraints and the value-for-money agenda, is it possible and feasible to improve access, services, quality and treatments without an additional investment? Is it
possible to spend more and spend it differently in order to achieve health gains in the long-term?

Conclusion
The move to Universal Health Insurance offers a number of challenges and opportunities for the progression of health services across the State. There are still a number of questions to be answered, stakeholder views to be considered, and issues and anomalies to be clarified and resolved, but progress is underway. As the representative group for Patients’ Organisations, Science and Industry, we agree with the fundamental principles around UHI and we stand ready to help and assist in any way we can. We believe that wide consultation, patient involvement and engagement at each step of the process are imperative. We are also of the view that the fundamental objective of the move to a UHI system should be to improve access to high quality health services and medicines for our citizens.