Submission from Cystic Fibrosis Ireland
Philip Watt  to: uhiwhitepaper

From: Philip Watt
To: uhiwhitepaper@health.gov.ie

1 attachment

UHI Final Cystic Fibrosis Ireland.docx

Dear Sir/Madam

Please find attached the submission for Cystic Fibrosis Ireland (CFI) on UHI

Kind regards
Philip Watt
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Dept. of Health
28/05/2014 15:41

28 MAY 2014

Universal Health Insurance
The Path to Universal Healthcare – White Paper on Universal Health Insurance: A policy submission from Cystic Fibrosis Ireland
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Acknowledgements

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Philip Watt
CEO
Cystic Fibrosis Ireland
Background

The Department of Health has published a White Paper on Universal Health Insurance. The White Paper sets out in detail the elements of the proposed Universal Health Insurance (UHI) model for Ireland. As such, it provides an overview on the overall design of the model, the proposed system for deciding on the standard package of services and the financing mechanisms for the system.

According to the Department of Health, this is ‘a most fundamental reform of the health system.’

The Department of Health has further indicated that it ‘is intended to establish a separate independent Expert Commission to examine the issues around the basket of services to be provided under UHI’ and within the overall health system. The Minister will announce details of the Commission in the near future and views on the basket of services will be sought by the Commission when it commences its consultation process. The closing date for submissions is 28th May 2014.

Cystic Fibrosis (CF) is the most common life-shortening genetic condition affecting Caucasians. There is a high prevalence of CF in Europe, with the highest worldwide prevalence in Ireland, which is three times the average rate in other EU countries and the United States. Approximately 1 in 19 Irish people are carriers of the altered CF gene, versus 1 in 25 in the UK.

A significant part of this submission provides an overview of the model and routines of CF care in Ireland. This overview will show that CF is very different to most other long term

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1 http://health.gov.ie/blog/publications/call-for-submissions-white-paper-on-universal-health-insurance/
2 http://health.gov.ie/blog/publications/call-for-submissions-white-paper-on-universal-health-insurance/
chronic diseases. This must be taken into account in all aspects of forthcoming health service reform (summarised in annex five) not just in relation to the proposed introduction on UHI.

This policy submission was approved by the Board of the CFI on 24th May 2014.
CFI Response to the White Paper on Universal Health Insurance

Cystic Fibrosis Ireland (CFI) welcomes discussion and debate on how the health system in Ireland is structured and financed. Our key concern, naturally, is how people with CF (PWCF) and their families will fare under the proposed new Universal Health Insurance (UHI). The short answer from the perspective of CFI, is that it is very unclear whether UHI will improve the care given to PWCF and their families and indeed there are a number of concerns that have already emerged and highlighted in this submission that would indicate that UHI could have a detrimental impact on CF care, in particular the potential undermining of the Long Term Illness Scheme (LTI) and the fear that as a consequence of UHI more of the financial burden of caring for someone with CF will be transferred to their families or to PWCF themselves.

The following are the key concerns of CFI. We reserve the right to add or withdraw these concerns as more detailed information about UHI becomes available.

1. Process and timescale for consultation: CFI is concerned about the very short period being allocated by the Government for the receipt of submissions to the White Paper on UHI. Given the fact that ‘this is a most fundamental reform of the health system’, CFI would contend that this consultative period is extended to at least September 2014. Further, the Department of Health should indicate a phased consultative period and similar views of key stakeholders should be sought when more information is released. Proposal: Extension of the initial consultative phase to September 2014 and the announcement by the Department of Health that further planned consultation will be undertaken by the government.

2. Little Detail: CFI notes that the White Paper is very short on detail, in particular from the perspective of CF and similar life-long hereditary diseases. Many references to long term/chronic disease in the White Paper are clearly not intended to be inclusive of CF. This should be a further factor in the Department of Health organising a phased consultative process that would take into account the diversity of needs that need to be met by UHI and other health service reforms. Proposal: Development of a phased consultative process, including with patient groups after each significant
stage in the development of UHI.

3. Other Models of UHI should be included as part of the debate: CFI notes the World Health Organization (WHO) has rated the French and Japanese social insurance models as being best practice models for positive health outcomes, and for the delivery of effective and equitable healthcare. While not necessarily endorsing either of these models in advance of detailed discussion and analysis, we believe that these and other options for moving forward should be put to the Irish people in the form of a Green paper. Proposal: The decision to offer only one model of UHI is disappointing as there may be better models in existence that will not be part of the public discourse. The Department should consider withdrawing the White Paper and presenting instead a Green Paper highlighting a range of options.

4. Recent evidence points to flaws in the Dutch Model of UHI: CFI notes that that only one model of Universal Health Insurance is being put forward by the Department of health for consideration. The model of UHI proposed draws heavily on the so called ‘Dutch Model’. CFI notes that significant criticism of the Dutch model that has emerged in the Netherlands and from outside analysts since its introduction. For example, there has been a rise in costs of insurance in the Netherlands by 40% over 4 years since 2009 and more recently there have been cuts in the range of care packages provided because of these rising costs. The Dutch model is now one of the most expensive health systems in the OECD. Health expenditure in the Netherlands ranks second in terms of percentage of GDP and fourth in terms of per capita spending. Many commentators in Ireland have further pointed to the very significant costs for bringing in UHI and the concern that this may further divert funding from where it is needed most- front line services. A key concern is that health insurance companies will be the major financial beneficiaries of this form of UHI Proposal: The Dutch model should be subject to greater analysis by the Department before it is adopted and other models of UHI should be considered (see also proposal 2).

5. Concern about the concept of a ‘health basket and Commission: CFI expresses strong concern in relation to the concept of a health basket that will include
approval of new therapies including drugs. The health basket model could very quickly move to a model of ‘health rationing’ or worse ‘health discrimination’ CFI is concerned that decisions on what goes in the health basket will not be a decision by the Department but by a separate independent expert commission. CFI is concerned that the composition or terms of reference of this commission may disadvantage long term diseases such as Cystic Fibrosis or orphan/rarer diseases in in Ireland, that are often costly to treat. CFI notes that some health ‘experts’ have in recent times have openly expressed the view that Ireland should be putting its resources into more common diseases as this will benefit more people. Policies based on such attitudes will have the potential to discriminate against long term and/or orphan diseases. Proposal: The Department of Health should continue to have direct responsibility for the health services provided for those with long term diseases and rarer/orphan diseases, including the approval of new therapies.

6. Concern about the future of the Long Term Illness Scheme: People with certain diseases, including Cystic Fibrosis can get free drugs, medicines and medical and surgical appliances for the treatment of that condition. These are provided under the Long Term Illness Scheme. This scheme is administered by the Health Service Executive (HSE), under Section 59 of the Health Act 1970. The Long Term Illness Scheme does not depend on your income or other circumstances. Many People with CF are also eligible for a Medical Card. Before the LTI scheme came into effect (1971) many families with CF were impoverished because they had to pay for virtually all their medical costs and CFI was one of the main reasons why there is a Long Term Illness Scheme. CFI is very concerned the LTI Scheme will be abolished by the Department of Health with the introduction of UHI and that the Department may use UHI to transfer costs of treatment from the government to people with CF and their families (see also annex four of this submission). Proposal: The Government should clearly indicate that the Long Term Illness Scheme will be retained and where necessary improved and there will be no attempt to dilute the support for services and treatment provided under the LTI Scheme.
Annex One: What is Cystic Fibrosis?

Cystic fibrosis (CF) is the most common life-shortening genetic condition affecting Caucasians\(^7\). There is a high prevalence of CF in Europe, with the highest worldwide prevalence in Ireland\(^8\), which is three times the average rate in other EU countries and the United States\(^9\). Approximately 1 in 19 Irish people are carriers of the CF gene, versus 1 in 25 in the UK\(^10\). When two carriers of the gene alteration parent a child, there is a one in four chance of the child being born with CF.

**Health Problems with Cystic Fibrosis**

![Image of health problems with Cystic Fibrosis](image)


Cystic fibrosis is caused by alterations in the cystic fibrosis transmembrane conductance regulator (CFTR) protein\textsuperscript{11}, which affects the regulation of absorption and secretion of salt and water in various parts of the body, including the lungs, sweat glands, pancreas, and gastrointestinal tracts.

In people without CF the CFTR protein controls the flow of salt and water through the body's cells, keeping mucus on the inside of the body's organs thin and watery. People with CF produce large volumes of thick, sticky mucus, which can clog airways and harbour harmful bacteria. Symptoms reported by people with CF vary significantly in severity, from very mild to debilitating. The most common symptom associated with CF is recurrent chest infection, which result in lung damage, with the majority of death's occurring through respiratory failure\textsuperscript{12}. Other medical issues associated with CF include; CF related diabetes, osteoporosis, malnutrition, liver disease and infertility, particularly in males. Since CF impacts on so many body parts at once – respiratory, digestive and reproductive – a specialised, multi-disciplinary team of health professionals is essential for the care of patients\textsuperscript{13}. This team generally consists of; CF specialist consultant, CF specialist nurse, Physiotherapist, Dietitian, Psychologist, Social Worker, Microbiologist, and Pharmacist.

Since the first description of cystic fibrosis, outlook for patients has improved dramatically. In the early 1930's, 70 per cent of people with CF died before their first birthday, in 1964 it was estimated in Ireland that 40% of children died before the age of 6\textsuperscript{14}. The median age of death has steadily increased in recent years from 17 years in 1994 to 23.5 years of age in 2011\textsuperscript{15}. There has been a steady increase in the number of adults with CF, thanks to improved care in recent years with 52% of the CF population in Ireland 18 years of age or over.


\textsuperscript{14} Watt, P. For the Roses. The Cystic Fibrosis Association of Ireland at 50. Cystic Fibrosis Ireland. (2013)

\textsuperscript{15} Cystic Fibrosis Registry of Ireland (2011) Annual Report
Annex Two: The Model of Care and Standards of Care for Cystic Fibrosis in Ireland

In 2005 Cystic Fibrosis Ireland (CFI) commissioned a report which evaluated ‘The Treatment of Cystic Fibrosis in Ireland: Problems & Solutions’ or ‘Pollock Report’ as it was better known, which highlighted a number of detrimental short-comings in the care being afforded to people with CF (PWCF) in Ireland. Too few staff and a shortage of adequate facilities and services were among the key findings of this report.

Subsequently, the HSE established a working group to review ‘Services for People with Cystic Fibrosis in Ireland’. This was carried out in 2008 which largely endorsed the model of care set out in the Pollock Report including the development of a network of specialised and shared care centres the development and resourcing of multi-disciplinary clinical teams.

The overall model of care for CF developed in Ireland is informed by the ECFS: ‘Standards of care for patients with Cystic Fibrosis’\textsuperscript{16}. It is important to note that this document is currently being up-dated to meet the needs of this changing patient population.

Standards of Care in Cystic Fibrosis Care
Designated Cystic Fibrosis Centres

\textbf{Functions of CF centre}

- Provide care and annual review of all patients

- Provision and co-ordination of a wide range of treatments and services which require special expertise in patients with CF

- Provision of expertise in specialised procedures

- Access to diagnostic and specialised laboratory facilities

- The provision of psychosocial support for problems specific to CF

- Ensuring smooth transition of patients from paediatric to adult care

- Liaison with transplant centres and assessment of patients
- Supporting patient advocacy
- Performing clinical research and presenting findings at various national and international conferences.

The CF centre should have the staff and facilities to provide comprehensive care and be capable of treating all CF associated complications. In countries like Ireland, where there is shared care between the CF centre and smaller hospitals which are closer to the patient’s home the centre should coordinate care and hold ultimate responsibility for the patient’s treatment and outcome.

Shared care centres must meet the same standards as at the main centre, allowing that this may require help from the multidisciplinary centre team and subspecialty consultations from the ‘main’ CF specialist centre. These conclusions and recommendations were ‘fully-endorsed’ by the HSE working group; “The practice of the CF centre sharing the care of patients with the staff at their local hospital has become established because some families and patients cannot, and others will not, travel long distances for their routine treatments”\(^{17}\).

It is positive that, according to the White Paper on Universal Health Insurance that; “The Government is committed to…… delivering proactive, integrated care at the lowest level of complexity that is safe, timely, efficient and as close to home as possible” (pp. 5 of UHI White Paper).

Staffing

The report produced by Dr R. Pollock ‘The Treatment of Cystic Fibrosis in Ireland: Problems and Solutions’, outlines staffing requirements for a CF specialist centre. At the centre of the accepted European model of care is the multidisciplinary team (HSE CF Services Report, 2009). It is important to note that these figures represent the minimum acceptable standards per 50 patients;

\(^{17}\) Services for People with Cystic Fibrosis in Ireland: Conclusions of a Working Group established by the Health Service Executive
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<th>Specialist Adult Centre</th>
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The staff-moratorium currently in place in the Health service has caused a great number of difficulties for PWCF and CF teams throughout Ireland – there are current vacancies/gaps in the care provided by key personnel in the management of CF. This is a grave concern for CF Ireland and must be addressed immediately by the Department of Health.
Annex Three: The Routines of CF care

The out-patient clinic

Patients should be seen every 1–3 months. Newly diagnosed infants or patients with severe disease should be seen more often. The outpatient visit should take place in a designated clinic in the hospital. The CF physician and nurse should see the patient and all other members of the CF team must be accessible. When indicated, the centre should have the ability to organise an admission (to a single, en-suite room) or home intravenous treatment.

OPAT

Cystic Fibrosis patients are one of, in not the heaviest users of the OPAT services in Ireland. This service is essential to ensuring patients receiving IV antibacterials, who could be treated out of hospital, remains an in-patient. Our patients value this service greatly. Some suggestions which would improve the clinical benefits for our members, as well as reducing the patient burden on the health care system include:

- Home visits by CF specialised physiotherapist. This will maximise patient recovery, eliminate/ significantly reduce the need to travel to hospital to receive physiotherapy care during IV treatments and increase the speed of recovery for patients.
- Home visits by nurses. This is a service which is provided on an ad-hoc basis which some patients are not receiving. A home visit from the nurse is essential to ensure patients are administering the IV antibiotic in an appropriate fashion and also to change cannula lines if necessary. Again this could prevent patients travelling long distances to have cannula lines changed.
- It is essential that this services is developed further under the UHI scheme as it has benefits for both the patient and the state.

In-Patient Care

A CF specialist centre must have sufficient beds available at all times to allow immediate admission. Each centre should have a clear infection control policy. The beds should be in single rooms, mainly to prevent cross-infection, and preferably with private en suite toilet and bathroom. Hand washing facilities and alcohol-based hand rubs must be present in each
patient cubicle. It is estimated that an average of 10% of CF patients are in-patient at any one time. This figure is variable and can increase significantly at times.

Access to Medications

Under the current health system PWCF access their medications through one of two means: Long-Term Illness Scheme (LTI) and/or the Medical card. It is of utmost importance that PWCF continue to receive all medications which are essential to the treatment of CF, free of charge. There is also a need for the Free GP visit card to be made available to all people living with chronic illness.

Access to high tech medication

Over the past year new therapies which significantly improve the quality of life and clinical outcomes for PWCF have been approved for use by the FDA and the EMA. These new therapies fall under the category of ‘personalised medication’, and are extremely expensive. It has been documented that cost-effectiveness assessments are flawed, and have only a limited role to play in reimbursement decisions for orphan drugs and beyond\(^{18}\). It is essential that UHI establishes a fairer method to evaluate the ‘cost-effectiveness’ of such therapies, for example, wider consideration of patient-reported outcomes.

Access to fertility treatment

As survival ages increase for PWCF due to constantly improving medications and standards of care, so too does the desire to start a family – something that was very much unheard of for PWCF years ago. Many people with CF cannot, as a result of their condition, conceive in the ‘normal’ way to have children of their own and may require assisted fertility treatment to do so. Approximately 98% of males with CF are infertile, normally due to absence of the vas deferens, a tube that carries sperm from the testis to the penis. Fertility problems in females with CF may be related to general ill health, poor weight, or poor control of CF-related diabetes mellitus.

Although symptoms that manifest in the respiratory and digestive systems are treated accordingly within the health service, complications linked to the reproductive system are overlooked. We contend that all aspects of care for a PWCF should be recognised and accounted for within the health service. Therefore, it is essential that fertility treatment for PWCF be provided by the state as it is a symptom caused as a direct result of having this genetically inherited disease.
Annex Four: The Long Term Illness Scheme

People suffering from certain conditions, including Cystic Fibrosis can get free drugs, medicines and medical and surgical appliances for the treatment of that condition. These are provided under the Long Term Illness Scheme. This scheme is administered by the Health Service Executive (HSE), under Section 59 of the Health Act 1970. The Long Term Illness Scheme does not depend on your income or other circumstances.

Many People with CF are also eligible for a Medical Card. Before the LTI scheme came into effect (1971) many families with CF were impoverished because they had to pay for virtually all their medical costs of those with CF. CFI are very concerned that the Long Term illness Scheme will be abolished or radically changed by the White Paper on UHI. CFI is concerned that the Department of Health will use the UHI to transfer a significant degree of additional costs of treatment from the government to people with CF and their families.

If you qualify, you will get a long-term illness book. This book lists the drugs and medicines for the treatment of your condition, which will be provided to you free of charge through your pharmacist. You do not have to pay a prescription charge for drugs covered by your long-term illness book. Other drugs and medicines not related to the specified condition must be paid for in the normal way.

The medical conditions that qualify under the Long Term Illness Scheme are:

- Mental handicap
- Mental illness (for people under 16 only)
- Diabetes insipidus
- Diabetes mellitus
- Haemophilia
- Cerebral palsy
- Phenylketonuria
- Epilepsy
- Cystic fibrosis
- Multiple sclerosis
• Spina bifida
• Muscular dystrophies
• Hydrocephalus
• Parkinsonism
• Acute leukaemia
• Conditions arising from use of Thalidomide
Annex Five: Summary of Emerging and Proposed Health Service Reform

The following is a brief summary of emerging and proposed overall health service reforms that provide the context for the introduction of UHI. Some of these policies have the potential to have a significant impact on CF care, depending on how well they are implemented. Other policies would appear to only marginal relevance to CF care. A key issue will be the level of resources that will be applied to implementing these emerging and proposed reforms.

Focus on Health and Wellbeing

A central plank of emerging health policy is that there needs to be much more focus on health promotion, protection and disease prevention, as opposed to the traditional emphasis on curative services. The publication of ‘Healthy Ireland - A Framework For Improved Health and Wellbeing’ and the subsequent establishment of a new Health and Social Wellbeing Division by the HSE, as well as a Health and Wellbeing Division within the Department of Health are outcomes of this policy.

Reforming Hospital Care

The Higgins Report is the Report on the Establishment of Hospital Groups as a Transition to Independent Hospital Trusts. The areas where this is most advanced appears to be in the Galway/North-West region and in the Greater Limerick/Mid-West region.

Reforming Primary Care

There is a commitment of making primary care free to all at the point of access, the new focus on primary care reform puts at its heart the notion of greatly improved Chronic Disease Management (CDM). The recent Department of Health publication ‘Future Health’. To date CF has not strongly featured in the priorities for reforming Primary Care probably because the model of care is significantly different than many other chronic diseases.

A New Integrated Model of Care

Integrated care means looking more at processes and outcomes of care rather than at structural and organisational issues. Typically, chronic diseases are where the challenges to
fully integrated care arise, with the focus often at the acute end of the spectrum. ‘Future Health’ pinpoints the need for much better performance in integrating care and identifies ways in which it will be promoted. These include clear policies with sharp KPIs attached, much more use of telehealth and telecare, introduction of Case Managers for patients with complex needs and co-morbidities, linking funding mechanisms with integration objectives, transfer of capacity and activity from the acute sector.

Patient Safety and Quality

HIQA has produced standards for better and safer healthcare, which in turn form the basis for national licencing of all healthcare providers in due course, starting with hospitals in 2015. Alongside this, ‘Future Health’ points to the establishment of a Patient Safety Agency in 2013 to boost patient advocacy and implement national quality and patient safety initiatives. National Clinical Programmes including one for CF have been developed to develop guidelines and Models of Care.