



# *IPPOSI Roundtable Meeting* **A Focus on Patient Compliance and Adherence in 2013**

## ***OUTCOME REPORT***

*An IPPOSI Roundtable Meeting for Patients'  
Organisations, Science and Industry members*



The Irish Platform for Patients' Organisations, Science and Industry is a patient-led partnership which provides a structured way of facilitating interaction between patients' organisations, science, industry members and where possible state agencies. We hope to ensure patients in Ireland have prompt access to new and developing innovative therapies



“

It is estimated that 20% to 30% of patients do not adhere to medication regimens that are curative or relieve symptoms, and 30% to 40% fail to follow regimens designed to prevent health problems. When long-term medication is prescribed, 50% of patients fail to adhere to the prescribed regimen.<sup>1</sup>

”

<sup>1</sup>“Improving the sustainability of healthcare systems through better adherence to therapies: a multistakeholder approach ” (CPME) (EPF) (EFPIA) (PGEU) [www.eu-patient.eu](http://www.eu-patient.eu).

## BACKGROUND

On June 27<sup>th</sup>, 2013, IPPOSI held a roundtable meeting entitled *A Focus on Patient Compliance & Adherence in 2013* at the European Parliament Information Office, Molesworth Street, Dublin 2.

According to the European Patients Forum website<sup>1</sup> - policy makers, health managers and healthcare professionals often underestimate the opportunity to improve health outcomes and rationalise health expenditure through monitoring what happens after a medicine has been prescribed.

It is estimated that 20% to 30% of patients do not adhere to medication regimens that are curative or relieve symptoms, and 30% to 40% fail to follow regimens designed to prevent health problems. When long-term medication is prescribed, 50% of patients fail to adhere to the prescribed regimen.

As a patient-led organisation, the board of IPPOSI identified a key need to discuss, highlight and seek solutions for this important issue. It thus put together a roundtable event consisting of all the relevant stakeholders in this issue – patients, health service providers, clinicians, policymakers, healthcare academia

and researchers, and the pharmaceutical industry.

This outcome report aims to inform key stakeholders on the facts concerning medication compliance, and highlights the areas where consensus has been reached. IPPOSI hopes it will encourage the putting together of a multi-stakeholder group to address the issue of treatment compliance and adherence and ultimately lead to improved outcomes for patients.

*Below: Ms Laverne McGuinness, Chief Operations Officer, HSE, Dr Ambrose McLoughlin, Secretary General of the Department of Health and Ms. Eibhlin Mulroe CEO of IPPOSI*



## EXECUTIVE SUMMARY

There were a number of key contributions made during the meeting, and all those in attendance were encouraged to join in the debate, with a number of contributions made from the floor.

### Key speaker contributors included:

- **Dr Ambrose McLoughlin**, Secretary General of the Department of Health
- **Dr Roisin Adams**, Deputy Head, National Centre for Pharmacoeconomics
- **Prof Seamas Donnelly**, Consultant Respiratory Physician, St Vincent's University Hospital, Dublin
- **Prof Ken McDonald**, Consultant Cardiologist, St Vincent's University Hospital, Dublin
- **Ms Kitty O'Connor**, CEO, Alpha One Foundation
- **Dr Frank Doyle**, Division of Population Health Sciences (Psychology), RCSI
- **Dr Colm Galligan**, Medical Director, MSD Ireland,
- **Prof Brian Caulfield**, ARCH Research Centres, UCD
- **Ms Naomi Fitzgibbon**, Cancer Information Service Manager, Irish Cancer Society,

This meeting discussed the patient and clinician experience behind medication compliance figures and debated the issue in the context of the overall provision of treatments. It sought to uncover why medication and treatment compliance can be poor and what can be done to improve it.

Chairing the roundtable discussion, Eibhlin Mulroe, CEO of IPPOSI, said all the stakeholders in the room wanted the same outcome, which is the best possible outcome for patients.

Dr McLoughlin, Secretary General of the Department of Health highlighted the leadership role of IPPOSI and its members 'as they ensure patients' interests are put first.' He stated that 'the Department of Health will maintain very close links with IPPOSI, so that as we move forward, the Department will benefit from its input into policy making and evaluation'. He also stated that on this issue of compliance, patients must be fully supported by their healthcare workers and families to adhere to the instructions of their treating clinician.

IPPOSI Chairman Mr Godfrey Fletcher said patients have to be at the heart of any moves to improve their compliance with treatment. He noted that poor adherence reduces the efficacy of the treatment for the



patient and increases the cost of care in the long term. From an industry point of view it is important that the patient is aware of any potential side effects and that these are managed correctly to prevent patients ceasing treatment or missing doses.

The meeting placed a spotlight on the background psychology of non-compliance, practical issues such as costs, education/communication needs, the long-term economical and health risk of prescribing therapies that are taken sub-therapeutically or not at all, the payer's perspective (HSE), the impact of health literacy, and how future technologies might address some of these issues.

Arising from the roundtable discussion, IPPOSI has identified a number of key recommendations and consensus points which were reached by those in attendance:

Principal amongst these recommendations was the need for a specific body or working group to be formed to address the issue of medication and treatment compliance in Ireland.

There was also agreement that specific and detailed, Irish research was needed examining the issues behind compliance failure across

preventative, chronic and acute treatment.

For a full list of recommendations see page 13.



## CONTRIBUTIONS

### Policymakers

The first speaker, Dr Ambrose McLoughlin, said the current strategy of Government is to keep the focus on patients. He stressed that given the finite resources the health services have access to, coupled with ever increasing demand, all clinical and policy decisions for patient care have to be evidenced based and justifiable.

Dr McLoughlin said Primary prevention and getting patients to accept responsibility for their own health and wellbeing is also a key driver of the current Government's healthcare policy. The issue of compliance is a key part of this so patients must be fully supported by their healthcare workers and family to adhere to the instructions of their treating clinician,

Pharmacists have a major role in medication compliance and should step further into that role and be proactive about ensuring high levels of adherence along with their doctor and nursing colleagues to get the best outcomes, he maintained.

Dr McLoughlin told the roundtable that prescribing guidance is also hugely important in this respect and a new guidance system for Irish prescribers is now being put together, which will look at the most cost

effective options for patients and allow more high-tech solutions to be funded for those patients that need them.

He urged all stakeholders at the meeting to encourage prescribers to move towards the most cost-effective options for patients and he praised the work of Prof Michael Barry in the HSE's Medicines Management Unit in identifying the most cost effective treatments and also highlighted the vital role of the Irish Medicines Board in this area.

He also confirmed the long-awaited Health Information Bill will be published by the end of October 2013. Answering questions on how treatment compliance could be improved, Dr McLoughlin said the health system must become a "listening" system that is understanding and responsive of the needs of patients and healthcare professionals.

### Patients' Organisations

The majority of the speakers highlighted various reasons for non-compliance, which shed useful light on understanding the issues at stake and coming up with solutions to improve treatment adherence and outcomes.

Ms Kitty O'Connor, CEO of the Alpha One Foundation who is also a

respiratory nurse, said treatment compliance is a complex area, and the patient is the real expert. She pointed out that treatment isn't just about medication, it covers diet and lifestyle interventions such as smoking cessation and alcohol reduction, physiotherapy and exercise programmes, etc..

Ms O'Connor said financial costs are one reason for poor compliance. She said a recent common trend, from her own experience, is an increase in calls to hospital clinics from respiratory patients seeking repeat prescriptions or antibiotics, in an effort to avoid the cost of attending the GP for the prescription.

She mentioned poor communication/ education as other contributing factors in poor compliance, but acknowledged that research has shown that even when this issue is addressed, compliance only improves by 5-10%.

In addition, Ms O'Connor suggested many patients are more likely to keep taking a medication where they see a positive, immediate effect compared to long-term preventative medications. Some patients have told her that they take a "holiday" from their medication, and some said they were embarrassed at first by using a nebuliser. She suggested clinicians need to be better trained on

improving compliance, and must engage more with patients when prescribing and ask them if they are going to take the medication.

Ms O'Connor asked if we are really listening to patients and do we really know why they are not compliant? Like a number of other speakers she identified the need to commission Irish research into this area.

Ms Naomi Fitzgibbon, Cancer Information Service Manager, Irish Cancer Society, said people seek health information in different ways, i.e. older patients use the phone to call the Cancer Society, while younger people go online and on social media.

She said inquiries from patients who have been diagnosed with cancer have increased in recent years, which she believes is due to them spending less time in the hospital environment compared to some years ago.

Ms Fitzgibbon said breast cancer patients in particular verbalise distress about the side effects of their medication; such as long-term secondary preventative drugs, which patients need to take for five years or longer, and the potential impact on their fertility. They thus frequently stop taking these drugs and do not tell their doctor for fear of being seen as a "bad" patient.

Other patients simply forget to take their medication, while some are fearful when they switch medications and are facing into unknown side effects, Ms Fitzgibbon said. With more oncology medications now becoming available in oral form, she said supporting and empowering patients to take their medication is vital.

### Psychology

Dr Frank Doyle agreed that treatment compliance is a very complex, multi-dimensional issue that is influenced by environmental, social and emotional factors.

Routine and social support play key roles in medication compliance, as does emotion, with depressed patients less likely to take their medications, he reported. Cognitive factors are also key; what the patient believes about the medication, as in do they believe they need to take it or do they believe it is addictive and taking a holiday from it makes sense, Dr Doyle stated. Sometimes poor compliance is unintentional and patients simply forget, or they are simply unable to use, for example, their inhaler properly, he noted.

Dr Doyle said using methods, like text messages, to remind patients to take medication would be useful for patients who are forgetful (unintentional non-compliance), but

would not be any use for patients who don't believe they should be taking it in the first place. For example, some patients believe their surgery has 'fixed' their problem and do not understand why they need to take medication afterwards, so challenging beliefs is key. Thus any interventions to improve compliance in unintentional and intentional patients must be different.

Recent research showed various interventions only increased adherence modestly at best, Prof Doyle noted. He also questioned whether pharmacists could significantly improve compliance, and asked if they had been trained adequately to do so and to really listen to patients on the issue.

His assertions on pharmacists were contested by representatives from the Irish Pharmacy Union (IPU) later on in the meeting. They said that pharmacists could improve compliance in a number of ways, and that they had been upskilled in recent years, with ongoing opportunities to do so in this area. Dr Doyle said this information had addressed his concerns.

Meanwhile, Dr Doyle raised concern that the new generic substitution legislation could impact negatively on treatment compliance.

The really important thing is to ask



patients what they believe and work from there, he said.

Ms Eibhlin Mulroe pointed out there are no health psychologists in the Irish public health system unlike in the NHS in the UK. Dr Doyle welcomed her point, and said that medication compliance is an increasingly important part of the role of health psychologists in the UK. They have the specific skill set and training to address this area and should be a part of the Irish health system too, he indicated.

#### **Clinicians and Innovation**

Prof Ken McDonald said non-adherence happens right across the board – in primary prevention, chronic and acute illness.

He noted patients are more likely to take their medication after an acute event, like a heart attack, but as time goes by are less dedicated to taking their “life saving medications”, with non-adherence rates of approximately 30% in his clinic. Of those, about 90% mention side effects as a key reason for discontinuation, Prof McDonald reported.

He recommended giving patients individual risk assessments for their conditions to improve treatment compliance, revealing that under a project he is involved in a simple

blood test is used to do just that. This test has identified patients with, for example, specific hypertension and diabetes risks, and the approach has resulted in improved cholesterol, blood pressure and heart rate management without any therapeutic changes, Prof McDonald said. In addition, he suggested using technology to monitor patient compliance and vital signs on a day-to-day basis in the home setting.

Professor Seamas Donnelly stated that patient compliance with their medication was a significant issue in his clinical respiratory practice. Research suggests that up to 30% of patients do not take their inhalers as prescribed. Non-compliant patients present to the doctor and often report that their condition is no better. This potentially leads to inappropriate escalation of therapies.

A significant clinical unmet need in the clinic is to document accurately when patients take their medication. Novel sensor technologies currently in development at UCD and in Ireland will significantly help with this problem. By identifying non-compliance we can avoid escalating therapy and exposing patients to an enhanced risk of side effects. By identifying these patients we can

design focused educational strategies to improve patients understanding and improve compliance.

### Lifestyle

Prof Brian Caulfield also highlighted that treatment adherence is not just about medicines; it is about other interventions including diet, sleep and exercise.

He pointed out that Irish adherence to the recommended amounts of weekly exercise are far worse than 50%, and poor diet is very common. This might not be seen as having an economic cost, but it actually has a very significant cost to society in the long term, which the rising rates of preventable chronic diseases show.

Prof Caulfield said most people do want to be compliant with their treatment and it is up to stakeholders to really engage with them and use whatever technological and medical advances and strategies we can to engage and support them and bring them into the centre of their own care. He defined connected health as the smart use of people, processes or data technologies to design a new form of proactive healthcare.

He gave a number of examples of using mobile phones and apps to let patients record their treatment activities, which have improved adherence rates. Prof Caulfield and Prof Donnelly have co-authored an

article entitled *What is Connected Health and why will it change your practice?*, which can be downloaded at <http://qjmed.oxfordjournals.org>.

### Economic costs

Dr Roisin Adams noted that medication compliance and adherence has a key impact on treatment cost-effectiveness, and therefore the work of the NCPE.

Dr Adams confirmed the NCPE is examining the issue of medication compliance with a view to developing interventions to improve adherence and outcomes, which will also save money.

She quoted a number of different studies highlighting poor long-term treatment adherence with breast cancer, osteoporosis and diabetes medication, as well as issues with statin treatment targets, all of which cause poor outcomes and more costs to the health system.

For example, the NCPE's research looking at whether breast cancer patients continued to have their prescriptions filled found 20% stopped doing so at one year, 35% over three years, and over 50% at five years, which would have a significant impact on survival rates, she told the roundtable. With Type 2 diabetes, about 40% of Irish patients were found to not be compliant after one

year of being diagnosed, while 30% of Irish patients on statin therapy were not reaching their targets, Dr Adams reported. Ireland spends over €100 million on statin therapy annually, she noted. Dr Adams supported calls for more research on why patients do not take their medication and the introduction of proven interventions to optimise compliance.

Dr Colm Galligan, Medical Director of MSD Ireland, reiterated that adherence is a very complex issue with no easy, “magic bullet” solution. He said while information is important, patient beliefs will always trump it. From the perspective of researchers and manufacturers of therapies, it is about getting the right patient on the right treatment to ensure the best outcomes, Dr Galligan said.

One in four Irish patients have poor levels of health literacy, which is directly linked to health outcomes and treatment costs, and needs to be addressed, he maintained. Dr Galligan said the pharmaceutical industry is constantly looking at ways of making medication easier to take for patients, such as blister packs, injector pens, etc.

Ms Mulroe said health numeracy can also be an issue in treatment compliance, with some patients not understanding their medication needs

to be taken a certain number of times per day and at set times.

#### Other contributions

A number of contributions were made from audience members at the roundtable. Mr Rory O'Donnell, a pharmacist and President of the Irish Pharmacy Union said pharmacists are often the first port of call for patients and could play a bigger role in treatment compliance. He called for the introduction of medication use reviews and a new medicines service in Irish pharmacies, saying they had had a positive impact in countries where they had been rolled out.

HSE Chief Operations Officer, Ms Laverne McGuinness said the Executive is keen to address the issue of treatment adherence given the “huge” cost of the State’s drugs bill – approximately €2 billion per year.

Taragh Donohue of Multiple Sclerosis Ireland reiterated that compliance with non-medication treatment such as physiotherapy can be very poor (50%), and said more needs to be done to understand what motivates patients and how to translate that into improving compliance.

Ms. Anne Lawlor of 22Q11 Ireland, who has a daughter with the rare condition, called for “advanced patient practitioners”, saying she felt patients would be more likely to listen to people who have the

particular condition as there is nothing more powerful than peer education.

Another audience member mentioned that certain things, such as accidents or illness, can impact compliance as can the onset of dementia and other cognitive issues.

### Patients

Some of the most enlightening contributions at the roundtable were the patient perspectives. Mr Paul Carey, who has Parkinson's Disease and is a spokesperson for Move for Parkinson's, highlighted that depression can be key risk factor for medication non-compliance. He said people diagnosed with chronic or degenerative diseases like Parkinson's have a high risk of developing depression, which must be realised by clinicians and actively addressed. He said patients should be referred to appropriate support groups for their condition, as they provide invaluable support and information and let the patient know they are not alone with their experiences.

Ms Caroline Heffernan, a spokesperson for Cystic Fibrosis Association of Ireland who has CF, said she is 95% compliant with her treatment, which takes about four hours a day to complete. Ms Heffernan said as CF is a genetic condition that needs treatment from

birth, children will take their attitude to compliance from their parents. As CF patients are now living longer, it is no longer about simply medicating them in childhood, they need adult advice, not being "told what to do", she maintained.

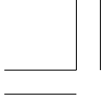

Ms Heffernan said treatment needs to be a partnership, adding that patients need encouragement not "a slap on wrist". She added that taking the 'odd day' off from a lifelong treatment is not necessarily a bad thing and sometimes patients simply need a break. Ms Heffernan also pointed out that any CF patients she knows who are taking the new CF drug Ivacaftor, branded as Kalydeco are very compliant, partly because they are aware of its very high cost. She suggested that patients should be told the cost of their treatment to help encourage compliance.

## POINTS OF CONSENSUS

Arising from the IPPOSI compliance and adherence roundtable meeting, the following recommendations and consensus points were reached by those in attendance:

- Poor medication and treatment compliance is a significant issue within the Irish health system, which affects patient outcomes and costs for the health service.
- Compliance and adherence are complex multi-dimensional issues with no 'one size fits all' solution.
- Treatment compliance and adherence does not just involve medicines, it includes medical devices, and diet and lifestyle interventions.
- A specific body or working group needs to be formed to address the issue of medication and treatment compliance and adherence in Ireland.
- All efforts to improve treatment compliance and adherence needs to be framed within the organisation of the healthcare system as a whole, and should involve all the stakeholders, from patients and the public, to health professionals, to policy makers and medicines manufacturers.
- There is a need for specific, detailed, Irish research examining the issues behind compliance and adherence failure across preventative, chronic and acute treatment.
- Patients must be at the heart of all research and interventions targeting compliance, and must be treated as individuals.
- Communication with patients and education on their treatment needs to improve. Patients need to be told exactly what each medicine/treatment does, and why they need to take it, not just be told 'take this'.
- Patients need to be asked about their compliance, and must be better educated about the outcomes of not adhering to their treatment.
- The impact of treatment side-effects on patients' lives has to be better understood, recorded and addressed.
- There is a need for increased education for prescribers and medication dispensers on improving treatment compliance, and they must be proactive in asking patients about their compliance.
- Health literacy and numeracy have a role to play in improving compliance and adherence.



- 
- 
- The issues of treatment compliance and adherence is not just down to doctors. Nurses and pharmacists have a bigger role to play though this needs to be done in an evidenced-based way and further training or protocols need to be drawn up.
  - There is a need for health psychologists to be employed in the Irish health system to address the psychological factors behind treatment compliance and adherence .
  - Technology has a role to play in monitoring and improving compliance and adherence
  - Patients must be empowered to take care of their own health and wellbeing, and to be more directly involved in their treatment decisions.



Irish Platform for Patients' Organisations, Science and Industry  
Camden Business Centre, 12 Camden Row, Dublin 8  
Tel: 00353 (1) 4790552 [www.ipposi.ie](http://www.ipposi.ie)