WEBINAR

PATIENT INVOLVEMENT IN HEALTH TECHNOLOGY ASSESSMENT:

International perspectives from CANADA, SCOTLAND & SWEDEN

INFORMATION FOR PARTICIPANTS

May 16th, 2018

#ACTIONonACCESS

AGENDA

Wednesday 16 May, 15:00-16:00 (Dublin time)

IPPOSI believes that to make robust recommendations and decisions, the processes used to assess and reimburse medicines must be inclusive. To be specific, they must capture (among others) the voice of the patient and the public.

In Ireland, we have yet to take advantage of the opportunities afforded by involving patients and the public in a *systemic* way across the *entirety* of the medicines assessment and reimbursement process.

Meaningful and sustainable public and patient involvement requires political, institutional and financial commitment. We are keen to learn from others who have already embarked on this journey to identify common pitfalls and to support the adoption of tried-and-tested approaches.

In autumn 2018, our patient members will be recommending a preferred course of action to our national authorities in the form of a 'Charter for Patient Involvement'. We expect that discussions during this webinar will contribute to the development of the Charter.

Facilitator: **Dr Derick Mitchell,** IPPOSI Chief Executive

Panel: **Sarah Berglas,** Patient Engagement Officer, Canadian Agency for Drugs and Technologies in Health (CADTH, Canada)

Jennifer Dickson, Public Involvement Coordinator, Scottish Medicines Consortium (SMC, Scotland)

Sophie Werkö, Patient Engagement Manager, Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU, Sweden)

Discussion: Questions and/or comments from the webinar audience

In August 2017, IPPOSI and MRCG published what is commonly referred to as the 'Drug Iceberg' report. The report is a summary of the discussions between Irish patient organisations during a roundtable on 14 June 2017. It makes a series of recommendations to government, pharmaceutical industry, regulatory bodies and patient organisations.

In February 2018, IPPOSI and MRCG published a second version of the 'Drug Iceberg' report. Report 2.0 puts forward a multi-stakeholder perspective on current levels of access to medicines in Ireland. It also shares good practice from other jurisdictions and explores case studies of patient involvement in Canada, Scotland & Sweden. A copy of the report can be found here.

IPPOSI has dedicated 2018 to the theme of Access to Medicines. Our work on this issue is described in more detail here.

Please join us in calling for improved access to new and innovative medicines for Irish patients in 2018.

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SCOTLAND

Jennifer Dickson joined the **Scottish Medicines Consortium** (SMC) as Public Involvement Co-ordinator in 2014. A member of the SMC executive team, her role is to strategically develop engagement of the public and voluntary organisations in the health technology assessment process for new medicines in Scotland, to ensure that the experiences of patients, their families and carers is a key part of SMC decision making. Jennifer has fifteen years experience in voluntary sector management, having set up and led a UK wide information, support and advocacy service for people affected by lung cancer. She started her career as a graduate in the NHS, working in clinical effectiveness at Glasgow Royal Infirmary.

Case study 1: Patient involvement in assessment

SCOTLAND:[8] Similar in scale to Ireland, Scotland offers a potential roadmap towards greater patient involvement in new and improved drug therapy assessment and reimbursement. A review of progress made by the responsible body – the Scottish Medicines Consortium (SMC) – was completed in 2014, and a strategy to inform future activities during the period 2014-2020 was developed. A Public Involvement Network (PIN) Advisory Group (comprising of representatives from key patient umbrella organisations and the SMC) continuously evaluates and improves upon how the public and patients are involved in assessment and reimbursement decisions.

Early communication encourages transparency, accountability and participation. A webpage listing the medicines scheduled for assessment is maintained to allow patients ample time to participate and gather relevant information about their conditions and treatment options. A monthly newsletter is circulated to establish regular, proactive communication with patient groups and provide relevant updates.

Participation is welcomed in various forms and patients have the opportunity to present written submissions and/or oral presentations. A guide, a video and a worked example provide patients with clear instructions on how to prepare submissions. Patients making submissions or presentations can be invited to appear before the SMC. During these encounters, a SMC public involvement team member is assigned to each patient representative to provide support and assistance.

All SMC meeting are open to the public and minutes are published on the SMC website. A factsheet explaining the process is provided to patients and/or members of the public seeking to attend SMC meetings. A summary of key points made by patient representatives is included in the final SMC recommendation.

CANADA

Sarah Berglas is a patient engagement officer at **Canadian Agency for Drugs and Technologies in Health** (CADTH) in Ottawa, Canada. She works with 140 patient groups to contribute to the CADTH Common Drug Review and pan-Canadian Oncology Review, and works with CADTH review staff and committees to integrate patient perspectives into assessments. Sarah also supports individual patients to contribute to CADTH early scientific advice and provides the secretariat for the CADTH Patient Community Liaison Forum. Prior to joining CADTH in 2010, Sarah worked for ten years in the private sector in the UK in healthcare public relations. Originally from Australia, Sarah has a BA and a BSc from Monash University, Australia and a Graduate Diploma in Public Policy Evaluation from Carleton University, Canada.

Case study 2: Patient involvement in assessment

CANADA:[9] Boasting a strong record of involving patients in medicines assessment, Canada shares many good practices to aspire to. A culture of partnership directs the work of the Canadian Agency for Drugs and Technologies in Health (CADTH) and patients are able to contribute alongside manufacturers and clinical and economic experts. Patients are not an afterthought; patients are consulted and engaged throughout the assessment process. For instance, patients are invited to join the early dialogue between CADTH and the manufacturer (aimed at preparing for an upcoming assessment). Patients are also decision-makers and seats are reserved for lay or public representatives on each of the CADTH Committees. A Patient Liaison Forum comprising of representatives from key patient umbrella organisations gives patients a voice in managing and improving the overall assessment process.

Canada has made several efforts to improve upon the traditional patient involvement model of posting public information and inviting written submissions.

Firstly, a collaboration between the CADTH and the Canadian Cancer Action Network (CCAN) – the Health Technology Assessment Patient Engagement Navigator – funds a dedicated patient involvement focal point tasked with helping patients to better understand and engage with the process. The Navigator helps individual patient representatives improve their submissions and works with patient communities more generally to identify ways in which patients can interact with the process.

Secondly, CADTH operates a feedback system which provides patients making submissions with a personalised response following the conclusion of an assessment. A letter details how assessors considered the patient input and shares any suggested improvements for future submissions.

Finally, CADTH publishes its recommendations in draft format to invite comments from manufacturers, patients and other stakeholders. When a recommendation is contested CADTH engages in a further review of the evidence before making a final recommendation. All evidence used to arrive at the recommendation is available for public scrutiny including the clinical and economic reviewer assessments, the manufacturer, advisor and patient feedback, and the names of the clinical and economic experts.

SWEDEN

Sophie Werkö was appointed Manager of International Relations at **Swedish Agency for Health Technology Assessment and Assessment of Social Services** (SBU) in 2012. She coordinates SBU's international work and leads on the patient involvement work. In the field of HTA in Sweden, she has experience of collaboration with patient representatives, mainly from work on HTAs within psychiatric care. Also experience from a Government Health Care Agencies Collaboration on work with users, patients and clients to develop a model on user involvement on the level of mutual work, which so far has been tested twice; once on the topic of mental ill-health and medication and once on mental ill-health in the Elderly. Since 2016, she has led the collaborative group of nine governmental agencies in the field of health and social care that work on patient and client involvement. Since 2014, Sophie is the Vice-Chair of *The International Network of Agencies for Health Technology Assessment, INAHTA*.

Case study 3: Evidence-based reimbursement decisions

SWEDEN:[10] Taking a different approach to many of its European peers, Sweden operates a **value-based pricing** model in assessing and reimbursing medicines for the Swedish market[11]. Since 2002, all public health decisions – including access to medicines – are evaluated against three ethical principles:

1. human value: everyone has a right to healthcare
2. need and solidarity: patients in the greatest need and vulnerable groups are prioritised
3. cost-effectiveness: resources are used effectively

There is an important hierarchy between the principles. For example, while it may be more cost-effective to treat more minor conditions, the principle of need and solidarity precedes the principle of cost-effectiveness and chronic and life-threatening conditions are prioritised.

Medicines are reimbursed if the Pharmaceutical Benefits Board (TLV) assesses that the price requested is justified on the basis of the pharmaceutical value delivered. The assessment looks at the value offered to the health system and the value provided to society in general – for example, patients may be able to return to work and be economically productive. While Sweden uses QALY to assess value, there is no strict threshold and issues such as disease severity and unmet need are taken into consideration. Sweden requires new medicines and medicines on the market to demonstrate value, and a review of all medicines eligible for reimbursement has been completed since a new pharmaceutical reimbursement policy was introduced in 2002. One patient organisation leader and one senior citizen sit on the Board charged with assessing value. Mindful of the need to continue to deliver value, the Swedish government has initiated an inquiry into how it reimburses, and prices drug therapies and a final report is expected in December 2018[12].