



Joining forces to prevent human papillomavirus (HPV)-related cancers in Europe

EU Stakeholder Roundtable

12 December 2017
Brussels, Belgium



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Foreword from the Chair



Dr. Lydia Makaroff

Europe has an unprecedented opportunity: to aim for elimination of HPV-related disease and end the misery it causes for our citizens. This meeting of experts and patient advocates highlighted a strong willingness to work together to make this a reality.

Building on Policy Recommendations developed by a panel of experts in the field, this meeting explored concrete ways to tackle HPV-related cancers through increasing coverage of HPV vaccination for boys and girls, and other steps such as improving access to cervical screening. As Director of the European Cancer Patient Coalition (ECPC), I was delighted to chair the meeting and pleased that patient voices were highly valued alongside health professionals, scientists and policymakers.

Despite the availability of a vaccine proven to be an effective primary prevention measure to reduce the burden of HPV-related cancer, as this report illustrates, many challenges remain to achieving universal, gender-neutral HPV vaccination in the EU. With addressing health inequalities being a key principle of the EU, there was universal agreement that inequality in access to cancer prevention is unacceptable. We cannot accept that boys and girls in some Member States are offered protection while others are not.

I was heartened by the commitment of the participants to work together in the future and identify a number of clear and tangible actions that will turn our words into action. We now have fresh momentum but we know that making a political impact in Brussels and EU Member States is not going to be easy, we must compete for the hearts and minds of policymakers in an environment that can be crowded and noisy. We can all recall stakeholder meetings that fail to deliver in the long-term. But there is a real sense that this time is different.

The recommendations in this report are not a wish list. They are practical and achievable steps that will reduce the burden of HPV and prevent cancers. For me, one of the key conclusions is that we must coordinate our efforts to maximise their impact. A 'scattergun' approach will not work.

To eliminate HPV-related cancers in Europe, we must establish an active coalition that consistently and powerfully makes our case where it matters. Our voices are loudest when we speak as one.

Dr. Lydia Makaroff

Director, European Cancer Patient Coalition (ECPC)

Chair, EU Stakeholder Roundtable event on preventing HPV-related cancers, 12th December 2017

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Roundtable Participants

Speakers

Name	Organisation	Country
Dr. Lydia Makaroff (Chair)	European Cancer Patient Coalition	Belgium
Professor Chris Bentley	PCBC Ltd.	UK
Dr. Xavier Bosch	HPV Prevention and Control Board	Spain
Gráinne O'Rourke	Irish Cancer Society	Ireland
Dr. Jennifer Blake	Society of Obstetricians and Gynaecologists Canada	Canada
Corie Leifer	International Papillomavirus Society (IPVS)	Netherlands
Peter Baker	HPV Action	UK

Guests

Name	Organisation	Country
Maude Andersson	Gynsam (Swedish Gynaecological Cancer Patients National Coalition)	Sweden
Marina Davidashvili	European Parliamentary Forum on Population and Development	Belgium
Rosybel Drury	MSD Europe	France
Edel Fitzgerald	ReputationInc	Ireland
Katie Gallagher	European Patient Forum	Belgium
Andrea Gerosa	Think Young	Belgium
Eduardo Pisani	MSD Europe	Switzerland
Charles Howard	Think Young	Belgium
Dr. Mario Preti	International Society for the Study of Vulvovaginal Disease (ISSVD)	US
Anna Rek	European Cancer Patient Coalition	Belgium
Ciara O'Rourke	MSD Europe	Ireland
Ico Toth	ENGAGE / Málvavirág Alapítvány – Hungarian Patient Association	Hungary
Dr. Alex Vorsters	HPV Prevention and Control Board	Belgium
Christel van Weert	Roche Diagnostics	Belgium
Dr. Wendy Yared	Association of European Cancer Leagues	Belgium

Opening

This Roundtable event, which took place in Brussels, Belgium, in December 2017, brought together a number of EU and national organisations and experts, to discuss how best to prevent HPV-related diseases for EU citizens.

Dr. Lydia Makaroff, Director of the European Cancer Patient Coalition (ECPC), a Brussels-based patient organisation and leading advocate for cancer patients, chaired the meeting.

She advised attendees that the objective was to identify the next steps required to achieve gender-neutral vaccination and access to cervical screening across all Member States and how the organisations represented could help meet the challenge and deliver upon a plan.

She reminded the group of the importance of continuing to combat HPV diseases through vaccination and screening.

Despite considerable advances in Europe, many challenges and inequities in access remain. In addition, public hesitation and unwarranted stigma around HPV disease and the vaccine remain a key contributor to low coverage rates in many EU Member States.

She stressed that patients should be at the centre of any discussions on HPV and HPV disease prevention. Preventing morbidity and mortality from HPV-related cancers can only be achieved by taking a comprehensive approach to addressing public hesitancy with regard to the vaccine, broadening access to both genders and encouraging uptake of available cervical screening programmes.

Dr. Makaroff also reminded participants of the value of speaking openly and freely. Group discussions were subject to the Chatham House Rule* and are therefore unattributed in this report.

*Meetings held under the Chatham House Rule allows participants to use the information received, but neither the identity nor the affiliation of the speaker(s), may be revealed.

Part 1: Gender-neutral vaccination: a matter of equality and equity



Dr. Xavier Bosch

HPV-related diseases, patient impact and prevention, presented by Dr. Xavier Bosch

Dr. Xavier Bosch is Senior Consultant, Cancer Epidemiology Research Programme at the Catalan Institute of Oncology and Director of the e-Oncology Department: PREC e-oncología - Leadership Team. He set out the burden of HPV-related diseases in Europe, the complexity of the HPV cancer landscape and his work in prevention. There was growing evidence that HPV represents a public health threat that should be addressed by vaccination.

The burden of HPV-related cancers

In Europe, an estimated 50,000 new diagnoses of HPV-related cancers occur every year. However, there are a further 6 million pre-cancerous lesions, all potentially requiring interventions - a significant burden on health services and individuals. There is also a shift in the types of cancers emerging. HPV-related oral and anal cancers are increasing, particularly in males. Oropharyngeal cancer rates, again particularly in males, are surpassing those of cervical cancer*.

The latest generations of the vaccine are virtually 100 per cent effective in women; rates of cervical cancer are falling. In addition, the effectiveness of vaccinating women in mid-adulthood - assuming no pre-existing pathology - is almost as effective as vaccinating at a younger age.

For males, there are relatively few trials of efficacy to date but those that have taken place are very promising, showing 90 per cent protection against genital warts and around 70 - 80 per cent against intraepithelial lesions in men who have sex with men (MSM). Yet, although the vaccine works in both adult women and men, the disease burden caused by genital warts in men is being overlooked, in spite of almost 700,000 cases annually.

The importance of breaking the chain of infection is almost as great as that of individual protection. Vaccinated individuals prevent the spread to subsequent partners, even where that partner is not vaccinated. Ultimately, this helps develop herd immunity, but it must cover both women and men.

The complexity of HPV-related cancers

Given the undoubted benefits of a cancer prevention vaccine, why do barriers to uptake exist? He suggested a number of reasons specific to HPV. First, rather than a single disease, there are several viruses posing different risks with latency from infection to disease. In addition, vaccination targets are unclear; coverage started with adolescent girls, moved to boys, then to adult women and most recently to high-risk groups.

Another issue is that there has not been sufficient time since the introduction of the vaccine to generate irrefutable evidence of the vaccine in cancer prevention. Currently, evidence relies on surrogate endpoints. This gap has been heavily exploited by anti-vaccine campaigners to great effect, increasing hesitancy and scepticism amongst the general public. The impact of this scaremongering cannot be overstated; Dr. Bosch cited the example of Japan, where coverage rates dropped to zero, over fears generated by anti-vaccine campaigners.

He stressed that the vaccine is so effective that maximising coverage could eventually eliminate cervical cancer, conceivably within a generation. Increasing vaccination will reduce both the amount spent on treating HPV-related diseases and the cost of testing and screening. However, to be truly effective requires identifying and acting on critical areas for expansion.

*Please note no HPV vaccine is indicated today for penile cancer, head and neck cancer or respiratory papillomastosis.

Part 1: Gender-neutral vaccination: a matter of equality and equity (Continued)



Grainne O'Rourke

Delivering and maintaining a successful and resilient HPV vaccination programme: the critical role of stakeholder collaboration, **presented by Grainne O'Rourke**

Grainne O'Rourke, Head of Communications at the Irish Cancer Society and HPV Vaccination Alliance in Ireland, explained how a collaborative, multi-stakeholder approach increased HPV vaccination uptake, following a sustained campaign by an anti-HPV vaccine group in Ireland.

Challenges to the Irish HPV vaccination system

The Irish HPV vaccination system, administering the vaccine to 12- to 13-year-olds through the school system, was seen as a major success story amongst its European counterparts. However, social media activity by well-organised anti-vaccine campaigners has caused a sharp decline in uptake.

The main driver for this, she believed, was not a failure of vaccination science, but rather communication of the benefits. Trust in traditional sources of medical information has declined as the relationship between the physician and patient has changed, meaning that potential patients – and their parents/guardians – now seek advice elsewhere, including online.

This allowed anti-vaccine campaigners to influence those that would usually seek protection through vaccination. Campaigners used language that engaged their intended audience, seeding doubt in the minds of concerned parents. Their highly effective use of emotional messages and personal stories, based on the perceived 'dangers' of HPV vaccination, resonated far more with audiences than the clinical, science-based approach used to support vaccination.

For the Irish Cancer Society and other pro-vaccine organisations, this highlighted a clear need to fight 'fire with fire', using emotion rather than pure science. There was an urgent need for the scientific and medical communities to learn to deploy messages that resonate with the audience without

being patronising. She estimated that around 10 per cent of the population were fundamentally opposed to HPV vaccination, with the same proportion fully in support. The target audience was the 80 per cent who were undecided.

Tackling negative sentiment through collaboration

The anti-HPV campaign in Ireland was beginning to affect uptake of vaccines generally. This prompted the Irish Cancer Society and a small group of concerned but determined experts to establish an 'HPV Steering Group', which led to a multi-stakeholder group, the HPV Vaccination Alliance, composed of 37 member organisations including cancer advocacy groups, academics, schools and pharmacies. There was strong media interest in the Alliance launch, as the group began engaging with the anti-vaccine groups in public debate.

This strategy and collaborative approach has proved successful: official figures indicate that vaccine uptake is rising again. Ms. O'Rourke believed that the success and sustainability of the Alliance stemmed from making it easy for members to remain involved. This has been achieved by ensuring their time commitment was manageable and did not overstretch them or their resources.

For further information, visit:
www.hpvalliance.ie or www.cancer.ie

Part 1: Gender-neutral vaccination: a matter of equality and equity (Continued)



Professor Chris Bentley

Achieving equality and equity through HPV vaccination, presented by Professor Chris Bentley

Prof. Chris Bentley, Expert Consultant on Health Inequalities is a member of the National Advisory Committee on Resource Allocation (ACRA) in England and chairs their Technical Advisory Group. He explained that he was already a vocal advocate, particularly of vaccination as his professional public health experience with refugees in Somalia had shown him first-hand how effective vaccination could be in reducing disease transmission, morbidity and mortality.

The importance of community protection

Prof. Bentley stressed that the HPV virus is highly infectious and easy to transmit skin to skin, increasing the reservoir of disease. Therefore it is vital to break the chain of transmission. Herd immunity from HPV vaccination is exceptionally valuable. However, vaccinating only one gender will never achieve the 80 per cent coverage required across the population.

Given that it is possible to vaccinate against HPV, Prof. Bentley believed that any woman who develops cervical cancer nowadays has really been failed by the system. He explained that although HPV screening in women is widespread, it is not possible to screen for all HPV infections, nor does screening prevent transmission.

HPV prevention in men presents a further challenge. Despite being a major source of HPV transmission, they are not screened at all. Vaccination offers the cheapest, most effective primary prevention option to avoid HPV-related diseases in men. Moreover, vaccination offers protection irrespective of lifestyle. People do not need to change behaviour, learn new skills or rely on particular resources. Affordability should not be an issue either.

Vaccinating boys early

Men who have sex with men (MSM) are 'outside the herd' in terms of protection. This high-risk, difficult to reach group often has limited early contact with sexual health services, experiencing higher rates of HPV and is at risk of exposure to complex interactions between HPV and HIV (Human Immunodeficiency Virus) infections. Early vaccination of boys provides protection in all scenarios, particularly before sexual orientation becomes clear. This is important, as they may have already been exposed to infection by then. It is another strong argument in favour of early, gender-neutral vaccination.

Protection across borders

Many men essentially 'borrow' their protection, i.e. they avoid HPV-related diseases thanks to the high coverage rates amongst women. However when they travel, they leave the community.

There are substantial variations in coverage rates between countries; a man entering a jurisdiction with lower coverage rates leaves his borrowed protection behind, and is again at risk while vaccinated, women retain theirs irrespectively. Achieving and maintaining equality of protection across the EU is therefore vital.

Part 1: Gender-neutral vaccination: a matter of equality and equity (Continued)



Peter Baker

HPV vaccination for boys and girls: Advocacy tools and key messages, **presented by Peter Baker**

Peter Baker, Campaign Director for HPV Action UK and an independent consultant on men's health, offered insights into advocacy for male HPV vaccination in the UK. He explained that 'HPV Action', a multi-stakeholder group of 48 patient and professional organisations, is pressing the UK government to extend the current HPV vaccination programme to boys. However, the government's vaccination advisory committee has been debating this topic for four years and has yet to make a decision.

Preventing HPV-related diseases: a holistic approach

One important reason for the delay in a decision to vaccinate boys is that health economists and accountants dominate the debate in the UK, a situation common to many countries. HPV Action argues for a more holistic assessment, extending beyond direct health costs and factoring in wider social and economic impacts as well as issues of equity and ethics. It is also important to note that vaccinating girls against HPV will not address the risks associated with men who have sex with men (MSM).

Advocacy in action

HPV Action undertakes a wide range of advocacy activities for gender-neutral vaccination, including booklets for the public and media outreach. Political advocacy is a key aspect of HPV Action's work, and recently a group of UK MPs (Members of Parliament) wrote an open letter to a leading national newspaper advocating for universal vaccination. The group also engages with the UK vaccination advisory committee.

Ideally, HPV Action would like to reach out to parents and boys directly, empowering them and encouraging them to demand access to the vaccine; however, resources are limited.

Currently, HPV Action is investigating whether vaccinating only women is ethically acceptable from a human rights perspective and whether it constitutes unlawful discrimination against males. The use of online petitions is another tool under consideration for raising awareness and galvanising support.

The impact of the work to date has delivered widespread support for gender-neutral vaccination from experts and policymakers in the UK. The tools HPV Action has developed have helped to make the case for gender-neutral vaccination through proven, effective arguments. Mr. Baker recommended a similar campaign at EU and Member State levels, pointing out that some countries, such as Austria, have already embraced vaccination for boys and girls and could provide a 'best-in-class' example.

Discussion

Other strategies for addressing potential barriers to HPV vaccination uptake, such as confidence in the vaccine, were highlighted. Denmark, which had also seen HPV vaccine uptake fall, has managed to reverse this trend. It used a relentless campaign based on communicating the science effectively, with a heavy reliance on social media. In Ireland, health authorities accepted that they needed to be more proactive in communicating on digital platforms about the benefits and safety of the HPV vaccine and so they invested in a campaign to build public confidence.

Targeted media engagement was discussed. Shifting the discussion to an emotional level can be challenging. While science and health writers understand many of the issues, taking an emotional angle can attract 'feature-style' journalists less familiar with the science that lies behind.

Another issue is poor vaccine take-up of healthcare professionals (HCPs): a number of HCPs are themselves declining vaccination, potentially undermining their credibility as advocates. In Italy, the government now funds HCP insurance, indemnifying them against any vaccine-related problems.

It was repeatedly stressed that messages need to be simple, e.g. 'this vaccine will stop you getting cancer' to counteract the impact of anti-vaccine scares.

Part 2: Inspirational initiatives: 'Looking beyond the EU'



Dr. Jennifer Blake

The Canadian experience, presented by Dr. Jennifer Blake

Dr. Jennifer Blake, Chief Executive Officer of the Society of Obstetricians and Gynaecologists of Canada (SOGC), is a leading authority on women's sexual and reproductive health. She explained how her country is aiming to address cervical cancer elimination, including initiating HPV Prevention Week and its impact.

Canada as a case study

Canada's approach to managing HPV differs to much of Europe. For example, screening is conducted by family physicians, referring to gynaecologists as required. However, reaching adequate levels of screening at primary care level could be improved.

Dr. Blake clearly remembered the point at which HPV and cervical cancer were recognised as sexually transmitted infections and the changes this prompted. After founding a survivor clinic, she realised the impact and the stigma surrounding the disease and this negativity created a personal sense of mission.

Currently, Canada is seeing similar patterns in HPV to those already discussed. Cervical cancer is falling, but this is mirrored by a rise in oral cancers, with the latter likely to overtake the former within 10–15 years. She believes that a safe and effective HPV vaccine is changing approaches to primary prevention. Screening forms part of secondary prevention, but presents its own challenges when undertaking cytology on vaccinated individuals.

Attitudes to vaccination and healthcare prevention

In general, people do not embrace health prevention, seeking solutions rather than taking action to avoid potential problems. In addition, stigma remains a major issue, with around 14 per cent of the Canadian population currently declining vaccination, albeit for a variety of reasons. Anti-vaccine attitudes are more common amongst the less well-educated, with immigrant status also

linked to lower coverage. The description 'HPV positive' adds to the hesitancy; it seems too close to 'HIV' positive and creates stigma for those with HPV-related diseases.

School-age vaccination has been repeatedly shown to be the only effective way to reach the relevant population. Yet vaccinating young people, primarily at the onset of puberty, can create an unnecessary connection between HPV and sexual activity. This could be avoided, as there is no need to wait until puberty to vaccinate.

It is important to position HPV as an infectious disease. Prevention is necessary for control, and the prevention mechanism must be evidence-based and economically sound. Dr. Blake questioned whether cancer control agencies were the right setting for vaccination. Although historically they provide cervical screening, they do not deal with the wider impacts, such as those on fertility, sexual health or quality-of-life. These issues are vitally important given the age at which HPV-related cancers can take hold.

Sensationalism in the media

One of the difficulties Dr. Blake highlighted was the nature of media. Positive media coverage on the benefits of vaccination is a challenge, with sensationalism offering a reliable way to boost page views. Generating such controversy often depends on creating a 'false equivalency' between anti-vaccine campaigners and genuine expert opinion. Such coverage creates uncertainty in the target population; faced with uncertainty the normal reaction is to do nothing, despite the

Part 2: Inspirational initiatives: 'Looking beyond the EU' (Continued)

increased risk.

A multi-stakeholder approach

When HPV vaccination became a priority in Canada, the SOGC forged partnerships with professional societies, industry, government and the public. This allowed it to convey simple, consistent messages through all relevant channels. The SOGC now has a voice at the policymaker table, as part of the National Advisory Council for Immunisation and provides input into the Canadian Partnership against Cancer.

The importance of simple, authentic messaging

Dr. Blake emphasised the importance of gaining trust through our communications. She highlighted the fact that we can influence and win hearts and minds by showing that we care, by saying what we say with authenticity and by acknowledging apprehension in others.

Soft skills are vital, particularly when gaining the trust of concerned people. We need to show that we genuinely care, that we are listening and that we truly empathise - and do so within the first 30 seconds. It is wrong to dismiss those that are anti-vaccine as eccentrics. In reality, they are genuinely afraid and their fear drives them to do what they do. It is vital to respond quickly, with relevant facts and data, but first we need to get them to listen. We have enough positive messages to make that happen.

Education and awareness-raising activities are also vital, but are not enough on their own; there needs to be other tactics. We need an evidence base to be credible, to advise with confidence and to be able to adapt to changing evidence. We also need support from other organisations. Involving women's health organisations will increase protection, accelerate HPV elimination and - perhaps most importantly - reduce stigma.



Part 2: Inspirational initiatives: Looking beyond the EU (Continued)



Corie Leifer

International HPV Awareness Day, 4th March 2018: promoting awareness of education around HPV infection, **presented by Corie Leifer**

Corie Leifer, from Kenes Association Worldwide, presented on behalf of the International Papilloma Virus Society (IPVS). Ms. Leifer explained that the role of the IPVS is to promote awareness of and education around HPV infection, how it spreads, and how HPV infection and the diseases that it causes can be prevented. As part of this mission, it is organising the first International HPV Awareness Day on 4th March, 2018 to raise awareness of the virus, the tools that exist to prevent it and to provide coordinated advocacy.

Partnering to raise awareness about HPV

International HPV Awareness Day aims to strategically unite HPV advocates, civil society organisations, governmental organisations, researchers and other stakeholders to prevent and fight against HPV-related cancers globally. The inaugural HPV Awareness Day furthers this goal by establishing a basis for communities, schools, clinics, universities and patient groups to enhance awareness and understanding of the virus. As part of this awareness-raising initiative, IPVS will create an alliance of organisations, each with a keen interest in tackling the HPV virus and reducing its global impact.

Two categories of supporters are anticipated: the first is open to academics, patient groups and non-governmental organisations (NGOs) - such as the participants at this meeting - that could become 'operating partners'. They have a steering role and are publicly recognised for their input. This allows them to expand their networks while allowing the alliance to access to their audiences. Through partnerships with other societies, institutions and organisations around the first HPV Awareness Day, IPVS hopes to improve knowledge on and spark conversation around HPV infection.

The second group would be composed of sustaining partners that contribute funding. They have 'arms-length' status, with no role in steering and no platform for promoting individual products, although their financial support will be recognised. Sponsorship from these associates will significantly extend the reach of the message promoted on International HPV Awareness Day.

Ms. Leifer urged attendees to join this initiative: to date, 25 organisations have signed up and made commitments to participate. In order to publicise the events being held by these groups, IPVS will circulate a unified portfolio of marketing initiatives covering a broad spectrum of activities that a wide range of organisations can actively engage on, at international, European, national and local levels, in order to galvanise maximum support for this first HPV Awareness Day.

International HPV Day will take place annually on 4th March. For further information visit www.givelovenothpv.org/ and <http://ipvsoc.org/>

Discussion and next steps

Identifying opportunities to reduce the stigma of HPV-related diseases is crucial, particularly on how HPV is described. Potentially, policymakers could be more willing to understand, and support, universal vaccination with the right communication tools and simplified messaging, such as, "It is a vaccination against cancer".

The ambitious vision to eliminate HPV in Europe could be a goal for policymakers to work towards.

Ensuring advocates are equipped to counter the arguments of anti-vaxxers is important, but not before demonstrating care, concern and empathy. Indeed, it is important to empathise with anti-vaccine campaigners; in many cases, their concerns represent genuine and strongly held fears.

Could the age of vaccination be reconsidered? The current age of vaccination policy unnecessarily links it to puberty and sexuality.

HPV awareness activities need to stand out clearly as a major health priority, given the competition for attention. While numerous opportunities exist for increasing awareness about HPV (such as the inaugural International HPV Awareness Day led by IPVS in March, Cervical Cancer Awareness Month in January, ECDC (European Centre for Disease Prevention and Control) Immunisation Week in April, European Week Against Cancer in May, and potentially a 'HPV Prevention Week' in October), the group agreed that a coordinated campaign would be more successful than a 'scattergun' approach.

A focus on HPV advocacy and awareness for one day should ideally be on the same day in each country, with a common theme and common messages (adapted to local needs/circumstances as required). Participants can in the first instance leverage the potential of International HPV Awareness Day, on 4th March, as a centrepiece, with other 'days' providing further promotion opportunities.

Participants agreed to liaise with their governing bodies and board on endorsing the EU Policy Recommendations and Call for Actions presented at the meeting, and assess how to increase advocacy activities for (gender-neutral) HPV vaccination.

Conclusions and recommendations

There was general agreement amongst the group that the following should be focused upon moving forward:

- Enhance recognition of the importance of vaccinating boys and increasing vaccine coverage rates to create true community protection for all European citizens.
- Review and modify HPV vaccination public policy across Europe in order to broaden access to boys and increase coverage rates.
- Improve communication skills and awareness-raising initiatives around the HPV virus as a priority, particularly online and on social media platforms.
- Provide policymakers with evidence-based information in a style and language that they can understand and re-use to support HPV vaccination.
- The possibility that HPV-related diseases could be eliminated in the future was viewed as a proposal that would appeal to policymakers and should be explored further.
- A coalition of multi-sector EU level stakeholders should be established to raise political and public awareness of HPV-related diseases and the efforts that are required to reduce their burden on patients and society.

Notes

- As the meeting was conducted under the Chatham House Rule, discussions, Q&A and recommendations are unattributed.
- The order of content has been edited slightly to improve the flow of this report.



For further information, please contact:

ReputationInc
6th floor, The Boat House
Bishop Street
Dublin 8, D08 H01F
Phone: 01 412 0500



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