Prevention and control of HPV and HPV-related cancers in Ireland and the UK : Lessons learned and the way forward

MEETING CONCLUSIONS

Dublin, Ireland

30 November – 1 December, 2017

Objectives of the meeting

- *Give an overview of the health care systems in both countries.*
- *Provide a summary of the epidemiology, burden of disease and surveillance related to HPV and HPV related cancers in Ireland and the UK.*
- *Discuss successes, topical issues and challenges related to HPV vaccination and screening particular to Ireland and the different regions in UK.*
- *Gain insight in the various stakeholder perspectives.*
- *Propose recommendations for the way forward.*

Health care system UK

- Universal access, funded by taxes.
- Patient at the centre.
- Focus towards local organisation.
- But: immunisation & screening national – part of specialised services (budget 15.4 Bn GBP).
- JCVI (NITAG) recommendation based on safety, effectiveness and cost-effectiveness.
- If recommendation beneficial for subpopulations, cost-effectiveness not needed.
- NICE – 20,000-30,000 GBP per QALI.
- Choice of vaccines -> Evidence-based policy making, rapid in practice.
- Immunisation = life course approach (cradle to grave).
- Would benefit from no further reforms, which distract from improving quality of care.

Health care system Ireland

- Free access to hospital.
- No universal access to GP / Medical services.
- Difficult access to secondary care – waiting lists.
- Voluntary health insurance to get quicker access to secondary care.
- Out-of-pocket payment rising.

Epidemiology, burden of disease, surveillance - Ireland

- Estimated 420 HPV-related cancer cases are caused by per year: 265 cervical, 69 oropharyngeal, 32 anus and rectum, 26 vulvar, 20 penile, 8 vaginal.
- Estimated up to 130 deaths per year.
- Number is increasing.

Epidemiology, burden of disease, surveillance - UK

- 83% of CaCx contain HPV 16/18.
- Large declines in HPV types 16/18, and 31/33/45, following the introduction of HPV vaccination.
- No evidence for type-replacement.
- Similar results for England and Scotland.
- Moderate decline in GW rates after 2vHPV, substantial decline after 4vHPV.
- Substantial decline in CIN2/3 diagnoses.
- Odds of 16/18 infection associated with CIN2+ reducing over time.

Epidemiology, burden of disease, surveillance - UK

- Strong evidence of herd protection: based on GW in males; HPV16/18 prevalence in unvaccinated women.
- Reduction in colposcopy work load and excisional procedures.
- Equity: vaccine effectiveness for high grade lesions was greater in women from the most deprived backgrounds.

Epidemiology, burden of disease, surveillance – Northern Ireland

- CIN3: 125.3 per 100,000.
- CaCx: 10 per 100,000; HPV16/18 in CaCx +/- 55%.
- Oropharyngeal cancer: 337/12 years, P16 positivity = 40.5%.
- No data on burden of vulval, vaginal, penile, anal or other HPV-related sites.

Prevention and control of HPV - UK

- Immunisation program since 2008.
- All girls aged 12/13 years.
- Catch-up campaign for girls aged 14-17 years.
- 2008 to 2012 - 2vHPV.
- 2012 – now – 4vHPV.
- 2014 from 3-dose to 2-dose.
- 2016 pilot MSM programme in GUM clinics.
- Coverage +/- 90%, completed in >85%, somewhat lower for Wales and Northern Ireland

Prevention and control of HPV - Ireland

- Immunisation program since 2010.
- All girls aged 12/13 years.
- 4vHPV.
- 2010-2014 Coverage >80%, completed in >97%.
- Drop to 50%, 15,000 girls not vaccinated in 2016/2017.
- Clear signs of increase in coverage .
- Screening since 2008.
- Jane Goody effect.
- Reaching >80% of target population .
- Aiming for careful, well-prepared switch to HPV primary screening.

Prevention and control of HPV - UK

- England - Aiming to go to HPV primary screening in 2019.
- Implementation plan.
- Wales – pilot study started in 2017, 20% of all samples.
- So far, 12% samples HPV+, referral rate 4.2%.
- Complete roll out October 2018.

Self-sampling in Scotland

- Self-collected vaginal sample using vaginal swab self-collection kit fulfils the criteria of international guidelines of HPV testing requirements for cervical screening.
- Vaginal swab maybe preferable over cervical smear, with lower potential for morbidity.
- In older (post-menopausal) women, vaginal sample (whether self- or clinician- obtained) may be more informative than cervical sample.
- Urine not adequately processed, but may still prove valuable.

Lessons learned

- School and health professionals trusted sources of information.
- Young people who received information about vaccines are more likely to consider them important.
- Most teenagers believe vaccines to be safe and effective.
- Social media may not have such as big an influence as previously thought.
- Parents and teenagers generally agree (on vaccination, at least).
- If there is no problem, don't create one by talking about it, when there is no issue, vaccination is not questioned.
- MSM programme in UK cost-effective due to high risk of HPV infection to these individuals.
- A response to issues on social media may make things only worse. Pick your battles carefully, when big, step in. Ask liaison to reply as well to form a front.
- Support frontline workers, if they are ill-equipped, everything falls apart. If they have questions, they can't inform others.

Lessons learned

- Political support is important. An outspoken Ministry of Health (MOH) can (help to) reverse a crisis.
- Not all journalists are equal: science journalists vs human interest journalists.
- Journalists can research and expose potential 'hidden motives' of anti-vaccine movements.
- If vaccine coverage is below 70%, boys less likely to benefit from herd protection. Parents seem less worried about safety when vaccinating boys.
- In LMIC girls may no longer be at school at the age of 12/13. A trial in 4-6 year-olds showed that immunogenicity was twice as high compared to 9-13 year-olds.

Lessons learned

- Gender-neutral vax needed:
  - To increase protection if coverage is low.
  - To protect MSM.
  - To improve resilience in case of coverage crisis.
  - To eradicate HPV (although challenging, given the number of HPV types).
  - (to protect boys in case of migration to non-vaccine regions, these may even be within one country).
- Do not underestimate the power of anti-vax groups.
- Do not rest on your laurels, act early, act fast.
- Bring (successful) science to the public, to immunize them against misinformation.
- Each crisis is also an opportunity, learn from it, and educate the public/media/politicians.

Challenges and opportunities in HPV control

- Vaccination in UK:
  - (Religious) schools without HPV programme.
  - Geographical variation in coverage.
  - Ethnicity and deprivation data not captured in routine coverage collection.
  - No consistent transfer from the child health information system (i.e. vaccination status) into the cervical screening programme.
  - Increased anti-vaccine activity.
  - Fear of needle may be more common than expected.
  - Impact of Irish issues on Northern Irish vaccine uptake, especially in border regions.
  - The language of vaccine safety is too complex for the public to understand, and may therefore make things worse -> head ache as a serious adverse event?

Challenges and opportunities in HPV control

- UK screening:
  - Difficulties to reach the target of 98% of women receiving their results within 14 days.
  - After switch to HPV screening: What is the impact of a positive STI result on a woman? Could that impact screening uptake?
  - How to manage women with persistent infection but normal cytology, risk of loss to follow-up.
  - Vaccinated women entering the screening programme, need for new approach.
- On (the role of) health care professionals (HCP):
  - Lack of support of vaccination by HCP.
  - Twitter by HCP does not reach the public.
  - Too little emphasis on prevention in medical curriculum (also pharmacist curriculum) – need to increase background knowledge for those in the front line.

The way forward

- Annual attitude survey among HCW, as a predictor of what is to come (HCW in the broadest sense, all active in vax field, including admin staff who pick up the phone).
- Switch to HPV primary screening.
- Need for triage test, but which one?
- Develop a children's book on immunisation.
- For LMIC: a single-dose, generic vaccine, in combination with a generic adjuvant, locally produced, may be the answer to the enormous burden of disease.
- Acknowledge that there are girls with health problems, the health care system provides no way to deal with them. Work towards a care pathway, to provide a place to go.
- Summer course on vaccinology, most that come have not had that info during their curriculum.

The way forward

- Prevention of anal cancer in high risk populations by vaccination, 2/3 of MSM would profit.
- More evidence needed for anal cancer screening strategy.
- In countries that start vaccination, why not vaccinate only boys, as carriers? Vaccine so effective that one gender vaccination suffices.
- Engage cancer survivors, they are the strongest advocates.
- Build an international network of cancer survivors, as they can coach and inspire each other.

Break-out group 1: important issues to take into account when considering gender neutral vaccination

- Cost and cost-effectiveness: look at projected disease levels, not just current disease burdens? Are analyses covering all the appropriate costs?
- What proportions of cancer do we attribute to HPV?
- Herd immunity – is vaccinating girls adequate.
- How best to protect MSM.
- Men who have sex with unvaccinated women; fluidity of male sexuality.
- What happens if HPV vaccination coverage in girls falls?
- Equality and equity; exclusion of boys as a matter of principle.
- Ethics / Law (is it unlawful to exclude boys).
- Eradication goal would reduce costs of screening, etc. (But eradication is challenging).

Break-out group 1: important issues to take into account when considering gender neutral vaccination

- Context is key - Complex question of country affordability.
- What is one trying to achieve? Control, elimination, eradication.
- Girls alone bearing burden of vaccination; relying on girls alone to take responsibility for sexual health (versus empowerment).
- Messaging important for gender neutral as a general anti-cancer vaccine (rather than anti-cervical cancer vaccine).

Break-out group 2: research topics to anticipate on future challenges and maintain good coverage

- Basic science:
  - Use of vaccines as therapeutic interventions.
- Vaccination – updating existing information:
  - Mechanism of effect in the immunized populations: dosage schedules (1 or 2 doses) & herd immunity/gender neutral vaccination.
  - Safety.
  - Extension of vaccination to other at-risk populations, for example transplant recipient.

Break-out group 2: research topics to anticipate on future challenges and maintain good coverage

- Implementation of HPV testing strategies:
  - Self-testing.
  - Triage.
  - Defining screening strategies in immunised populations.
- Understanding the dynamics of HPV infection:
  - Natural history studies to define better transmission (non-sexual).
  - Examine the factors encouraging cervical infection – auto-innoculation following sampling.
  - Communication of this to population to promote understanding & uptake of HPV control strategies.

Break-out group 3: lessons learnt from Ireland how to mitigate a crisis

- In Ireland, the upcoming harm of the anti-HPV vaccination lobby was underestimated.
- The power of social media was not recognized early enough.
- Ireland is beginning to avert the crisis / it takes sustained effort.
- Public perception fueled by REGRET that promotion of the HPV vaccination campaign was funded by Merck/GSK contributed to the crisis. Public health actors should have been more upfront to tell the public that this was false.

Break-out group 3: lessons learnt from Ireland how to mitigate a crisis

- Focus groups indicated that the Irish respect the official position of WHO concerning HPV vaccination more than they do the position of Irish officials.
- Unlike the situation for other vaccine-preventable diseases the public has little perception of the importance of HPV infection. This calls for information campaigns.
- Physicians and healthcare providers have limited time during a primary care consultation to assuage parents' concerns / they are not paid for the counselling time.
- As the crisis evolved public health staff were initially unsure about the adverse events and thought they were real and much worse than their superiors made them believe.

Break-out group 3: lessons learnt from Ireland how to mitigate a crisis

- Recommendations:
  - be more proactive; use a war games perspective.
  - Include a budget for communication/education when launching a campaign.
  - Adopt a proper framework for surveillance of social media.
  - Acknowledge the symptoms/syndromes of those affected by them.
  - Create informative websites.
  - Educate teachers, they are the line of first resistance against anti-vaccine activism.
  - Restore confidence among public health staff. They were initially unsure about the adverse events and thought they were real and much worse. Clear messages circulated within the first response team are important.
  - In school-based vaccination programs, messages must be prepared on a timely basis and a close link with school officials should be maintained.

Break-out group 4: how to convey 'success' of the vaccine program to support future engagement (and to overcome spurious claims)

- If we keep talking in the way we've been talking we will continue to have problems.
- Face to face communication very important-- make sure HCWs can talk about the issue appropriately—reach as many staff as possible—teach them stories to tell too.
- Ideally we will reach many groups—politicians, local journalists, clinic admin staff. This is resource intensive so we must find ways to cost-effectively amplify and expand your messaging.
- Tell emotive stories—involve cancer survivors, family members left behind, awfulness of the disease--be sure to hit emotions before sharing data.
- Tell success stories – numbers of cancers avoided – and how many people would get cancer if one doesn't vaccinate.
- Be more assertive and confident in your presentations when appropriate, even if your scientific training works against bold statements because the public reads "we are 98% sure" as "they are not sure and the opposite is possible."