

**HPV Leaflets Pre-test
Summary Report**

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APPENDIX – THE LEAFLETS AND Q&A SHEET

1. Introduction, background, objectives, method and sample

1.1 Introduction

This document summarizes findings from a pre-test of alternative leaflets to support the uptake of the new Human Papilloma Virus (HPV) Immunisation Programme.

1.2 Background and overall research aim

The Scottish Government announced on 26 October 2007¹ that it has agreed to introduce a new vaccine in Scotland against HPV. This decision follows advice from the Joint Committee on Vaccination and Immunisation² (JCVI), the independent expert body that provides advice on vaccines, that there is sufficient evidence on the protective effect of HPV vaccines against cervical cancer to proceed with an immunisation programme in the UK.

Commencing in September 2008 this new programme, recommended to be delivered mainly through a schools-based programme, is intended to protect girls by routinely immunising them at around 12-13 years of age, with the aim of preventing them from developing cervical cancer later in life. There will also be a one-off immunisation catch-up campaign for older girls.

Draft materials have been developed by the Department of Health in England to support the introduction and implementation of the new HPV vaccine to enable the target cohort of girls and their parents/carers to jointly make informed choices about accepting the offer of immunisation. Similar information will also be required in Scotland. These leaflets have been pre-tested in England and NHS Health Scotland wish to conduct a pre-test to assess whether these materials are suitable for adaptation for use in Scotland.

The intention is that this leaflet will be provided in advance of offering the first dose of the 3-dose schedule, and be specifically intended for the support of the immunisation-uptake decision. The Q&A Factsheet will provide additional background information. These leaflets will be one important element of a more comprehensive communications strategy.

The main aim of the pre-testing research was to assess the acceptability and communications effectiveness of the proposed new information leaflet - with alternative presentations - among the target groups and provide guidance on the optimization of this resource.

Research was designed to determine if, and to what extent, the leaflet provides young people and parents with what they believe they need to know – and in an accessible form – such that they can make an informed decision about having the vaccination.

¹ <http://www.scotland.gov.uk/News/Releases/2007/10/26114714>

² <http://www.advisorybodies.doh.gov.uk/jcvi/mins20jun07.htm>

1.3 Pre-test research objectives

A series of specific objectives were set:

- To identify the most effective leaflet for the target groups.
- To determine whether one leaflet is sufficient for all target groups.
- To assess the alternative leaflets among the target groups for:
 - clarity of language
 - signposting
 - ease of comprehension
 - tone
 - appropriateness, accessibility, appeal.
- To identify areas that require further information and/or clarification.
- To determine best delivery routes/sources of additional information i.e. Q & A fact sheet.
- To assess, broadly, the likely take up of the vaccine and how this might be maximised.
- To identify in particular any barriers to take up and provide suggestions as to how these might be overcome.

1.4 Method and sample

Eight focus groups were conducted in total; each lasting 75 minutes and with 6-8 respondents.

There were four groups among girls in the routine target cohort i.e. S2, 12-13 years:

- Girls, ABC1, rural Fife.
- Girls, C2DE, Edinburgh.
- Girls and mothers, C2DE, Wishaw.
- Girls and mothers, ABC1, Paisley.

Two groups were conducted among the younger catch-up cohort i.e. S3/S4, 14-16 years:

- Girls, C2DE, Paisley.
- Girls and fathers, ABC1, Edinburgh.

Two groups were conducted among the 16-17 years cohort. The groups included a mix of young women both in and out of education.

- Girls, ABC1, Wishaw.
- Girls, C2DE, rural Fife.

The sample included representation from minority ethnic and faith groups. And fieldwork took place in January 2008.

1.5 Stimulus materials

Stimulus materials consisted of an information leaflet with 3 alternative covers/designs:

It's a Girl thing (Girl Thing).
Pink
Leap

Order of introducing and discussing the covers was rotated across the sample to minimise potential order bias. Conceptual content was covered most fully via the first leaflet in the rotation. All leaflets were explored for presentation issues such as targeting, signposting, tone, acceptability, appeal.

Additionally, a Q&A fact sheet was explored by the target groups.

2. Summary

The leaflet *It's a Girl Thing* performed best among the S2 routine target cohort and largely meets the set communications requirements.

Research determined that there is no need for a separate leaflet for parents and daughters in the S2 routine cohort. However, additional information and reassurance for both parents and daughters is necessary.

Some of the issues or questions arising from reading the leaflets are adequately answered by the Q&A sheet for most of those seeking added insight e.g. more detail on safety of the vaccine.

Research suggests that other issues, such as the new and relatively complex concepts introduced to the 12-13 year olds targeted, seem to require alternative communications methods e.g. talks in schools, to cover them adequately and appropriately.

To emphasise to parents in particular that the vaccination is essentially intended to protect against cervical cancer rather than against STIs, consideration should be given to producing a mass media campaign whose role is to help reassure parents and further 'normalise' the vaccination programme.

In response to the communication of the leaflet, additional issues emerged that could prove to be barriers to uptake and require to be anticipated and managed:

- The suggestion that the vaccination is effective for only five years, leading some parents of S2 girls to consider waiting until their daughters are older to have the vaccination given that they will still only be 17 when they need a booster.
- Drop out after the first dose in the 3 dose schedule.
- Concern that the vaccination - as protecting against an STI - might promote promiscuity. It is difficult from this research to predict how widespread this concern might be, but research does indicate that it will be held strongly.

It's a Girl Thing is the preferred leaflet, and for similar reasons as expressed by the youngest girls, of C2DE girls in both older catch-up cohorts.

However, it was rejected as a design by ABC1 girls in these cohorts as 'trying too hard' to appeal, with these respondents also perceiving it to be insufficiently 'serious'.

The strength of rejection of *It's a Girl Thing* design/presentation by ABC1 girls (and their parents) in the catch-up cohorts makes it difficult to recommend it for these groups.

Older ABC1 girls and ABC1 fathers interviewed favoured *Pink* as achieving a better balance tonally, together with more appropriate targeting, for the older cohorts of girls. However, *Pink* is not as approachable and therefore not acceptable for older C2DE girls.

Several practical improvements were suggested by respondents across the sample to optimize the leaflet and it is recommended that these be implemented e.g. to layout for ease of absorption and retention of the information.

The pre-test research indicated that any HPV vaccination leaflet must also clarify implications for sexually active young women i.e. answer the question "will the vaccine still be effective for the sexually active"?

3. Detailed findings

3.1 Potential barriers to uptake of the vaccination

Having read the leaflet in detail, very few barriers remained according to 12-13 year olds in the routine cohort. Those that did were fear of injections; fear of side effects. A few suggested they might not have the second and third injections if they find the first injection to be a bad experience.

Most girls interviewed from across the sample claimed they had learned enough to decide and were likely to have the vaccination.

However, research indicated that through close reading of the leaflets by girls in the youngest two cohorts in particular these concepts are both new and complex (e.g. cervical screening) and require more explanation than is likely to be achieved by a leaflet. A few parents suggested this might prove to be a barrier to having the vaccine and recommended talks in schools to explain and reassure their daughters further.

Barriers emerged and were expressed by individual parents:

- Need for more detailed information e.g. names of the different viruses.
Parents are perhaps seeking additional reassurance as much as information.

- Need for more reassurance that this is 'normal' i.e. just another routine vaccination; especially to allay the concerns of some that the vaccination might be misinterpreted as "for sexually active girls".
- Long-term side effects e.g. after ten years rather than after five years as indicated in the information provided.
- Anticipated difficulties in persuading daughters to complete the course, leading to the question – "Is there any point in them having only the first vaccination?"
- Effective for only 5 years before perhaps requiring a booster indicated to one group of S2 mums and daughters that their 12 year old daughters would still only be 17 and (hopefully) not yet sexually active at the booster stage. This provided a rationale to some for waiting to give the vaccination to "older" girls e.g. 16+.
- One ABC1 mum of an S2 girl, who was particularly concerned about vaccinations generally, wanted an alternative protective approach e.g. test for the virus and treat that rather than have a mass vaccination programme.

A suggestion, interpreted by some of the older girls on reading the leaflet, that the HPV vaccine might not 'work' on those who have been sexually active, risks becoming a barrier to uptake of the vaccination for sexually active young women.

3.2 Contextual insights

The leaflet introduced completely new concepts to S2 girls: human papilloma virus; cervical cancer and cervix; genital warts; cervical screening; anaphylactic reaction. The term immunisation was also unfamiliar to many and vaccination was unfamiliar to some.

Research also indicated that some concepts are also very complex e.g. only some of the viruses cause cervical cancer; vaccination greatly but not completely reduces risk; the relationship between the virus and sexual activity; that the vaccination is most effective before the start of sexual activity; the relationship between sexual activity and the need for cervical screening.

Most mums claimed that these complex concepts are very difficult for S2 girls to understand and certainly too difficult through a leaflet alone. They suggested talks in schools to explain, familiarize and reassure their daughters.

A minority of mums commented that their daughters in S2 are too young to have to deal with these concepts with concern centering on the need for the vaccination at age 12-13 i.e. perceived as (well) before they are sexually active. The explanation for targeting this age provided by the Q&A fact sheet largely resolved this issue for those interviewed but it will likely emerge when the programme is underway.

The language in the leaflet was acknowledged as fairly simple and easy to understand. However, an impression remained for several S2 girls of “a lot of big words”. Research suggests this outstanding dissatisfaction is with the unfamiliarity and complexity of concepts rather than the language used in the leaflet.

Awareness of concepts e.g. the link between the virus and cervical cancer, is only marginally higher among parents and the older girls. A few parents mentioned recent press reports of the vaccination programme.

Most of the oldest girls had heard of cervical cancer - fewer among the S3/S4 girls; but depth of knowledge was low. Similarly the girls had little insight into cervical screening.

Neither the parents nor these older girls claimed to take issue with the need for them to understand all of these concepts better.

3.3 Comprehension of leaflet content

3.3.1 Key messages

All three leaflets successfully communicated:

- A new vaccination is being offered to 12-13 year olds girls.
- The vaccination prevents most (70%) cervical cancer.

It's a Girl Thing relayed this quickest via the cover phrase *Get my jab today to reduce the risk of cancer later in life*. This efficient communication of an important message was seen as a key strength for several girls and mums.

3.3.2 *Beating cervical cancer* on the front cover

Almost all research participants interpreted this in conjunction with the statement about the new HPV vaccination protecting against or preventing cancer.

A few across the sample initially expected information in the leaflet to be about curing or fighting cancer or perhaps coping with it i.e. a leaflet for cancer sufferers. However, further reading successfully clarified this.

3.3.3 *All you need to know...*

This passage was clearly understood, although only a few parents had heard of the new HPV vaccination.

On comprehension of, and preference for, the alternative terms ‘vaccination’ and ‘immunization’: most girls know or work out that they mean the same; ‘vaccination’ is more familiar to most. (Jab is the most familiar term.)

There was a preference to stick to one term i.e. vaccination, though the whole issue of terminology was not particularly involving or ‘vexing’ for respondents.

3.3.4 *Immunisation the safest way to protect your child*

This phrase naturally targets the leaflet at parents and not for girls themselves. However, a few respondents noticed the lack of consistency between this and paragraph 1 on page 3 which is clearly and exclusively directed at the girls.

3.3.5 *Phrase It's a Girl Thing*

The title phrase indicated that this is a leaflet for teenage girls. As such, it could provoke the question and discussion - why is the vaccination programme not targeting boys? This was usually resolved by thinking through to cervical cancer prevention, though a few mums persisted that the better approach would be to offer it to boys as well – to prevent them from contracting the virus (or worse) and reduce its overall prevalence.

3.3.6 *The essential guide to...*

There were no comprehension issues with this statement. *The essential guide* is a familiar phrase suggesting the information would be comprehensive.

Reference to 12-13s would need to be modified for older cohorts.

Research participants – especially parents and older girls - welcomed the early reference to the website for further information.

3.3.7 *Cervical cancer*

Suggestions came from across the sample to tighten the link between the terms 'human papilloma virus' and 'HPV' by capitalising the first letters in the phrase. Colour highlighting them in *Girl Thing* achieved this to an extent.

There was a mixed response to highlighting *around 1000 women die...* in *Leap* i.e. it was seen as either increasing the impact and memorability of what is seen as a key message; or as risking scaremongering.

3.3.8 *Diagram at Figure A*

This diagram was well received, especially by those S2s and S3/S4s who had no knowledge of the cervix or its position in the body.

Some rejected the diagram in *Pink* criticizing the colours as making the diagram less clear.

Many respondents suggested increasing the size of labels on the diagram in *Girl Thing* to make them easier to read.

3.3.9 *How cervical cancer spreads*

This was perceived as a very long, and for many girls, daunting paragraph. And participants suggested layout changes to improve ease of reading as well as aiding comprehension and retention of this complex information. For example by

breaking the paragraph up e.g. with bulleting (suggested by the oldest girls); by highlighting in colour the key messages.

Because it is so common, most of the population will get infected at some point in their lifetime. This phrase caused confusion and alarm and sometimes disbelief, in one to two girls in most groups who identified the “it” referred to as cancer rather than the virus. Rewriting this to remove the confusion is recommended.

No respondents commented on the concept of cervical cancer “spreading” even though this is not an accurate description.

3.3.10 *The HPV vaccine*

Respondents understood the reference to 70% effectiveness.

Research indicated no awareness of cervical screening among S2 girls; and greater awareness but no depth of knowledge of it among the older cohorts. On reading this section some older girls asked for clarification of *when you’re older?* – i.e. what age is that?

A few mums of S2 girls commented that age 12 or 13 is too young to have to deal with the concept of cervical screening. While it prompted a discussion among other mums that age 20 is too late to start having cervical screens when some young women are sexually active before that age.

The recommendation from research is not to change the text here but to prepare for further questions about cervical screening.

3.3.11 *Having the vaccination*

This is seen as another long and dense paragraph by many across the sample that would benefit from being broken up to ease absorption and retention of information.

It raised a series of concerns and questions that the leaflet does not (and possibly cannot on its own) answer.

One (BME) mother of an S2 girl reported that the leaflet and the vaccination risked promoting promiscuity. This was not mentioned by other parents, or any girls, in the sample.

There was concern among some girls and ABC1 fathers that the vaccine could be misperceived as for sexually active girls and that this must be avoided. This group suggested a media campaign to present the vaccination as routine and normal, always emphasising cancer prevention.

Targeting 12-13 year olds as pre-sexually active is understood but some mums continued to be uncomfortable about introducing 'difficult' concepts to such a young age. While at the same time, the oldest C2DE girls claimed to know sexually active 12-13 year olds and suggested targeting younger.

It is not clear what 'happens' if a young woman has been sexually active before she is offered the vaccination and questions were asked across the sample though most urgently and of most concern to girls in the older cohorts. For example - Will the vaccination still work? Will it still be offered? And if it does not work is there any no point in having it?

The Q&A sheet does not answer these questions adequately for respondents. Clarification of the implications for sexually active young women is essential or it could prove a significant barrier to uptake, at least among the oldest catch-up cohort.

3.3.12 You will need three injections

This section was easily understood and readily recalled; and while a preference for one injection was expressed most accepted the explanation of the need for three.

Mention was made by the S2 girls and S3/S4 C2DE girls of a serious risk of drop off after the first injection if it proved to be particularly unpleasant. And this concern was reinforced most strongly by C2DE mums who anticipated trouble persuading their daughters to complete the course and suggested this might be exacerbated by being given in school i.e. encouraging mass negativity and rejection.

These mums recommended delivering the course through GPs. However, there is no research evidence to believe uptake would be better via GPs.

3.3.13 Your parents will be told

This was readily understood. It was expected by the S2 girls, and was acceptable to parents and to S3/S4 girls.

However, the oldest cohort objected to this passage, recommending that they themselves rather than their parents be notified when their vaccination is due.

It raised the issue for oldest girls about best delivery method for the vaccination. They recognised that a school delivery is easy and offered the support of peers. While an invitation by letter addressed to the young women at home to attend their local clinic/GP was seen as the only obvious method for those who had left school.

3.3.14 Side effects

There were no identified comprehension problems with this passage.

It did raise the inevitable, often the only, concerns among the youngest girls about disliking needles/injections, risk of collapsing, etc.

In response to the phrase *Thousands of young women in the United States*...most recognised and accepted this as reassurance on safety of the vaccination i.e. it was tried and tested. But two ABC1 mums wanted more detail on this and asked “Why is it not millions? How has it been followed-up?”.

The Q&A information sheet provided sufficient additional information, and most importantly perhaps, reassurance for these respondents

One ABC1 dad remained concerned about the potential longer term side effects and would seek information beyond the Q&A sheet e.g. from the website suggested on the sheet; from US and Australian websites.

The reference to *young women* in US and Australia – otherwise *girls* in the leaflets – prompted a mum to ask their age with the implication that they were older than the proposed target age in Scotland.

There was a preference by S2 girls to be referred to as *girls* and 16-17s as *young women* throughout. There was no clear preference among S3/S4s.

3.3.15 *Missed your appointment*

Most accepted this paragraph though few questioned why it was included in this leaflet.

3.3.16 *Consent*

This section presented no comprehension or other problems for the vast majority of those interviewed.

Parental involvement in the decision to have the vaccination was not questioned. This was likely influenced in part by the discussions being conducted in parent/daughter groups.

Most parents of 12-13s fully expected largely to make the decision for their daughters. Their daughters and those S2 girls interviewed among peers, agreed with this.

ABC1 dads (prompted by one dad only) discussed, and were uncomfortable with, the suggestion that their 14-16 year old daughters could consent to the vaccination, or indeed to any medical procedure, without parental input. This will likely emerge as an issue for some parents; though the leaflet does not exacerbate it.

3.3.17 *More information*

12-13 year old girls and most 14-16 year olds largely felt they had learned enough to decide whether to have the vaccination or not. Parents usually wanted to know more, or be further reassured, on issues outlined earlier. The oldest girls were also likely to seek additional information.

The website is an acceptable source of information.

There was a request by C2DE parents (and a few individuals from across the sample) to provide the Q&A information sheet with the leaflet; or at the very least have it available at schools.

The GP was also considered a reliable source of additional information and reassurance, especially for the oldest girls.

3.4 Response to Q&A fact sheet

All parents and at least one group from each age range of girls explored the Q&A fact sheet.

It adequately answered outstanding questions on types and names of cancer causing viruses; details on the numbers of girls who have been given the vaccine internationally; follow-up studies on international programmes along with web references; the rationale for vaccinating 12-13 year olds.

However, it was not seen as answering questions on:

- Efficacy of the vaccination among those who have been sexually active?
- Longer term side-effects; suggesting to some that no answer is available on this yet.

Some girls saw contradiction in the Q&A sheet statement that “as much as half the population will be infected at some time in their life” (p2) compared with the reference to “most of the population” in the leaflets.

The Q&A information sheet also introduced for one group of parents of 12-13s the suggestion that the HPV vaccination might only last five years and therefore be ineffective before these parents would expect their daughters to have become sexually active. This led at least one C2DE mum to decide that her daughter would not need the vaccination until she was older. Discussion of this mother's decision, in turn, encouraged other mums in the group to reconsider their earlier decision to consent.

3.5 Response to design or presentation of the leaflets

3.5.1 *It's a Girl Thing*

This leaflet design was preferred by the routine cohort of girls. It was seen as having the best and a strong tonal balance between ‘serious and informative’ with ‘approachable’ and with ‘new and relevant’.

The NHS Scotland logo on the cover communicates provenance which is seen as important; indicating as it does that the information comes from an expected, trustworthy source and that it will be accurate and reliable.

The phrase on the cover - *Get my jab... to reduce risk of cancer* was seen as making clear the purpose of the leaflet for respondents.

The design concept itself – the writing, mirror, language – is seen as friendly and well-targeted “like something we’d write”; unlike the norm for NHS/health leaflets; and making it all seem less “scary”.

The presentation is seen as age appropriate for 12-13 year old girls and strongly so.

A few C2DE 12-13s would push the informality of tone and ‘girly’ theme further e.g. make it pinker. However, this is not necessary for most in the routine cohort and if implemented would risk undermining both the seriousness of the communication and of the decision about the vaccination.

There was a preference for the foldout over the booklet format with the former being seen as shorter and less formal.

No signaling problems emerged in the research.

Respondents from across the sample welcomed the handwritten headlines as providing both signaling and tonal benefits. There was however, a problem for a few with the legibility of the word *Beating* at the top of each page. And a few respondents read *jab* as *job*. Both terms would benefit from being written more clearly.

Highlighting *By having the vaccine* on page 2 of *Girl Thing* was appreciated given this is seen as a key piece of information.

C2DE girls in the older cohorts responded similarly positively towards *Girl Thing*, especially to its informal, friendly tone. And the lack of photo of a girl seemed to allow for a broader target age range and included those in our sample aged up to 17 years.

However, ABC1 girls (and dads) in the older groups rejected *Girl Thing* as “trying too hard” to appeal to teenagers in terms of its girly design references. The tone for them was seen as patronizing and “juvenile”.

Moreover, the phrase *By the way, the vaccine won't protect against other sexually transmitted diseases...* in being seen as offhand, even “cheeky”, reinforced the perception that the balance between serious and approachable had been undermined by this design.

Each of these ABC1 groups preferred *Pink* as a design.

3.5.2 *Pink*

On the positive side, for this design presentation:

- A clean, clear cover layout.
- A foldout format
- Larger writing (than *Girl Thing*).
- The orange page layout – suggesting this is particularly important info by being presented differently.
- Colours which are appealing and pink and targets girls without being ‘too girly’.
- Photo which was interpreted as friendly, relaxed, there is nothing to worry about/reassuring, these girls are supportive of one another.
- More conventional and serious than *Girl Thing* (for ABC1 older girls).

On the negative side:

- More conventional and less approachable than *Girl Thing*.
- Girls look aged 15+.
- Girls look like models i.e. alienating, according to the C2DE girls interviewed.
- Gleaming smiles which some saw as more appropriate for a dentist leaflet.
- Dense writing and “boring” layout inside.
- NHS logo being on the back when it is better placed on the front.
- Orange page was usually read as p4, which is not as intended.

Two alternative photos were examined in the groups. One featured two girls facing one another, with a clear view of one girl. This was seen as more ‘realistic’ than the original photo and to that extent was more appealing for some. But again the girls seem to be aged 15 years or even older and can suggest that the leaflet is targeted at these ages rather than younger.

Also, this photo seems to have lost its relaxed tone and the idea of supportive friends suggested by the original test photo. It communicated to a few girls that the topic of the leaflet might be bullying or mental health.

For the reasons outlined, this photo is not an improvement over the original photo.

A further alternative photograph was tested but rejected. The girls featured were described as 12 year old at most and to that extent not ideally suited to the target groups. Additionally, for some respondents the girls featured looked ill at ease or tense and this was considered inappropriate.

3.5.3 *Leap*

Leap was the least well received presentation of the leaflet by respondents from across the sample.

The conventional, 'health information leaflet' colours, NHS logo and fonts on the cover were seen as tonally serious, overly so for some. The perceived attempt to balance this with age appropriate appeal and approachability is not achieved; largely because the featured photos do not communicate as intended and are actively disliked.

The photos were seen as not well targeted with the girls being older than 12-13, usually in their late teens, sometimes older. The girls actions were also criticized as being inappropriate e.g. leaping about, as if in a jeans ad, going too far to be positive.

While the majority of respondents favoured alternative fold-out formats over the booklet format of *Leap*, C2DE mums of 12-13s (and most of their daughters who were happy to be led by their mums) preferred this over alternatives as reassuringly familiar as a "health leaflet".

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