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HPV Leaflets Pre-test Debrief

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Aim of the research

- ◆ To pre-test a new leaflet to support the uptake of the new Human Papilloma Virus (HPV) Immunisation Programme.
- ◆ Assessing the acceptability and communications effectiveness of the proposed new information leaflet with the target groups.
- ◆ And providing guidance on the optimisation of this resource.
- ◆ Research aimed 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.

Research objectives

- ◆ To identify most effective leaflet for the target group.
- ◆ 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.

Research objectives

- ◆ Specifically to probe on:
 - References to “girl”, “woman”, “child” in leaflets.
 - References to “immunisation” and “vaccination”.
 - Understanding that there are three injections.
 - Understanding of implications for those sexually active.
 - Understanding of need for ongoing screenings.
- ◆ Determine best delivery routes/sources of additional information i.e. Q & A fact sheet.
- ◆ To assess, broadly, 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

Method and sample

- ◆ 8 focus groups in total, each 75 minutes and with 6-8 respondents.
- ◆ 4 groups among girls in the routine target cohort - S2, 12-13 years:
 1. Girls, ABC1, rural Fife.
 2. Girls, C2DE, Edinburgh.
 3. Girls and mothers, C2DE, Wishaw.
 4. Girls and mothers, ABC1, Paisley.
- ◆ 2 among the younger catch-up cohort - S3/S4, 14-16 years:
 1. Girls, C2DE, Paisley.
 2. Girls and fathers, ABC1, Edinburgh.
- ◆ 2 among the 16-17 years cohort – both in and out of education.
 1. Girls, ABC1, Wishaw.
 2. Girls, C2DE, rural Fife.
- ◆ Sample included representation from minority ethnic and faith groups.
- ◆ Fieldwork took place January 2008.

Stimulus materials

- ◆ 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.
- ◆ A Q&A fact sheet.

Summary

- ◆ *It's a Girl Thing* is strongest for the S2 routine target cohort.
- ◆ And largely meets the communications requirements.
- ◆ No need for separate leaflet for parents and daughters in S2.
- ◆ But additional information and reassurance for both parents and daughters necessary.
- ◆ Some issues are adequately answered for most of those seeking them by the Q&A sheet e.g. more detail on use and safety of the vaccine.
- ◆ Others – such as the new and relatively complex concepts introduced to 12-13 year olds - seem to require alternative communications methods e.g. talks in schools.
- ◆ Consider a mass media campaign to help reassure parents and further 'normalise' the vaccination programme as essentially protecting against cervical cancer vs. against an STI .

Summary

- ◆ Additional outstanding issues will need to be anticipated and ‘managed’ e.g. potential drop off after the first of the three vaccinations.
- ◆ *Girl Thing* is the preferred leaflet, and for similar reasons, of C2DE girls in both catch-up cohorts.
- ◆ But rejected as a design by ABC1 girls in these cohorts as ‘trying too hard’ to appeal – over familiar, insufficiently ‘serious’.
- ◆ Older ABC1 girls and ABC1 fathers interviewed favoured *Pink* as achieving better balance tonally and more appropriate targeting.
- ◆ Outstanding issue requiring most attention for 16-17 year olds, and some younger girls, is the implication for those who are already sexually active – will the vaccine still work?

Potential barriers to uptake of the vaccination

- ◆ Very few barriers remained according to 12-13 year olds in the routine cohort:
 - Fear of injections.
 - Fear of side effects.
 - A few suggested they might not get beyond the first injection if they have a bad experience.
- ◆ Majority claimed they had learned enough to decide and were likely to have the vaccination.
- ◆ However, research suggests through close reading of the leaflets by girls in the target group that these concepts are both new and complex (e.g. cervical screening) and require more explanation than can be achieved by a leaflet.
- ◆ A few parents suggest this might prove to be a barrier to having the vaccine and suggested talks in schools to explain and reassure further.

Potential barriers to uptake of the vaccination

- ◆ Further barriers for individual parents:
 - Need for more detailed information e.g. names of the different viruses – perhaps as much seeking additional reassurance as information.
 - Need for more reassurance that this is normal/just another vaccine – especially to allay concerns of some that it might be misinterpreted as for “sexually active” girls.
 - Long-term side effects e.g. ten years vs. five years on.
 - Anticipated difficulties in persuading daughters to complete the course – “Is there any point in having only the first vaccination?”

Potential barriers to uptake of the vaccination

- ◆ Additionally:
 - “Effective for only 5 years” (as interpreted by one group) – 12 year old daughters would still only be 17 and (hopefully) not yet sexually active when need a booster. Provides a rationale to some for waiting to give the vaccination to “older” girls e.g. 16+.
 - If particularly concerned about vaccinations generally - one ABC1 mum wanted an alternative approach e.g. test for the virus and treat that rather than mass vaccination.
- ◆ Suggestion emerging from interpretation of the leaflets, that the HPV vaccine might not ‘work’ on those who have been sexually active risks becoming a barrier to uptake for sexually active young women if it remains unresolved.

Detailed findings

Contextual insights

- ◆ Leaflets introduce completely new concepts to S2 girls:
 - Human papilloma virus
 - Cervical cancer and cervix
 - Genital warts
 - Cervical screening
 - Anaphylactic reaction
 - Immunisation was also unfamiliar to most
 - Vaccination – unfamiliar to some.

Contextual insights

- ◆ Research suggests some concepts are also very complex:
 - Only some of the viruses cause cervical cancer
 - Vaccination greatly but not completely reduces risk
 - Relationship between the virus and sexual activity
 - Vaccination is most effective before the start of sexual activity
 - Relationship between sexual activity and need for cervical screening.

Contextual insights

- ◆ Most mums claimed these complex concepts are too difficult for S2 girls to understand – certainly through a leaflet alone.
- ◆ Suggested talks in schools to explain, familiarise and reassure.
- ◆ Minority commented that their daughters in S2 are too young to have to deal with these concepts:
 - Concern centres on need for the vaccine at age 12-13 (well) before they are sexually active.
 - Q&A fact sheet largely resolved this.
 - But it will emerge as an issue requiring management.

Contextual insights

- ◆ Language in leaflets acknowledged as fairly simple and easy to understand.
- ◆ But impression remained for several S2 girls of “a lot of big words”.
- ◆ Research suggests this outstanding dissatisfaction is with unfamiliarity and complexity of concepts rather than communications effectiveness of leaflets.

Contextual insights

- ◆ 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 dads nor these older girls claimed to take issue with the need for them to understand all of these concepts better.

Comprehension of content – 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* – and this was a key strength for several girls and mums.

Comprehension of content of sections

Beating cervical cancer on the front cover

- ◆ Almost all interpreted this in conjunction with statement about new HPV vaccination as protecting against or preventing cancer.
- ◆ A few across the sample initially expected information in the leaflet about curing or fighting cancer or coping with it i.e. a leaflet for cancer sufferers.
- ◆ Further reading successfully clarified this.

All you need to know...

- ◆ Clear – although only a few parents had heard of the new HPV vaccination.
- ◆ On vaccination and immunisation:
 - Most girls know/work out that they mean the same.
 - Vaccination is more familiar.
 - (Jab is most familiar of all.)
 - Preference to stick to one term i.e. vaccination.
 - Though no strong involvement with this terminology issue.

Immunisation the safest way to protect your child on front cover of Leap

- ◆ Targets leaflet at parents and not for girls themselves.
- ◆ But this conflicts with paragraph 1 on page 3.
- ◆ Seemed to add little to understanding or reassurance.

Phrase *It's a Girl Thing*

- ◆ Indicated a leaflet for teenage girls.
- ◆ Could provoke question and discussion - why not targeting boys?
 - usually resolved by thinking through to cervical cancer prevention.
 - 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 overall prevalence.

The essential guide to...

- ◆ Clear.
- ◆ *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.
- ◆ Welcome early reference to website for further information.

Cervical cancer

- ◆ Suggestions across sample to tighten link between human papilloma virus and HPV by capitalising the first letters in the phrase.
- ◆ Colour highlighting in *Girl Thing* achieved this to an extent.
- ◆ Mixed response to highlighting *around 1000 women die...* in *Leap*:
 - Increases impact and memorability of what is seen as a key message.
 - Risks scaremongering.

Diagram at *Figure A*

- ◆ Diagram well received – most S2s and several S3/S4s had no knowledge of cervix or position in the body.
- ◆ Some rejection of diagram in *Pink* – colours make it less clear.
- ◆ Many suggested increasing size of labels on *Girl Thing* to ease reading.

How cervical cancer spreads

- ◆ Perceived as a very long, and for many girls, daunting paragraph.
- ◆ Participants suggested layout changes to improve ease of reading...and of comprehension and retention of complex information :
 - Break it up – bulleting suggested by oldest girls
 - Or colour highlight key messages.
- ◆ *Because it is so common, most of the population will get infected at some point in their lifetime:*
 - Caused confusion and alarm, sometimes disbelief, at this statement in 1-2 girls in most groups when identify “it” as cancer rather than the virus.
 - Recommend rewriting this to remove confusion.

The HPV vaccine

- ◆ Clear on 70% effectiveness.
- ◆ No awareness of cervical screening in S2.
- ◆ Greater awareness but no depth of knowledge among older cohorts.
- ◆ What age is *when you're older?* - asked by some older girls.
- ◆ Mention by a few mums of S2 girls that age 12 or 13 is too young to have to deal with this concept.
- ◆ Raised for discussion among C2DE mums that 20 is too late for start of cervical screens when some young women are sexually active before that age.

- ◆ Do not recommend changing text here but to prepare for questions about cervical screening.

Having the vaccination

- ◆ Perceived as another long/dense paragraph across the sample (that could be broken up to ease absorption and retention of information).
- ◆ Raised a series of concerns and questions that the leaflet does not (cannot?) answer.
- ◆ One (BME) mother of an S2 girl reported that the leaflet and the vaccination risks 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.
 - Suggested a media campaign to present the vaccination as routine and normal, always emphasising cancer prevention.

Having the vaccination

- ◆ 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 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.
- ◆ Question asked from across the sample; most urgently/of most concern to girls in older cohorts.
 - Will the vaccination still work? Will it still be offered?
 - And if it does not work there’s no point in having it.
- ◆ Q&A sheet does not answer this adequately.
- ◆ Clarification of implications for sexually active young women is essential or it could prove a significant barrier to uptake – among oldest catch-up cohort at least.

You will need three injections

- ◆ Understood and readily recalled:
 - 1 injection is preferable but most accepted explanation for three.
- ◆ Mention among the S2 girls and S3/S4 C2DE girls of serious risk of drop off after first injection if it is particularly unpleasant.
- ◆ Concern reinforced most strongly by C2DE mums who:
 - Anticipated trouble persuading daughters to complete the course.
 - Suggested this might be exacerbated by being given in school – mass negativity and rejection.
 - Recommended going to the GP for the course.
- ◆ But no research evidence to believe uptake would be better via GP.
- ◆ Problems around completing the course of three injections needs to be anticipated/managed.

Your parents will be told

- ◆ Understood and expected by the S2 girls.
- ◆ And no problems mentioned by parents or S3/S4 girls.
- ◆ Oldest cohort objected to this, recommending that they themselves be notified when their vaccination is due.
- ◆ Raised issue for oldest girls about best delivery method for the vaccination:
 - Via school recognised as easy and offered support of peers.
 - Via letter (and leaflet) addressed to the young women at home to attend their local clinic/GP had support.
- ◆ Latter seen as only obvious method for those who had left school.
- ◆ But also preferred by majority of ABC1 young women still at school who see having the vaccination as a personal decision and did not want to risk undue influence from school staff or peers.

Side effects

- ◆ No comprehension problems.
- ◆ Raised inevitable, often the only, concerns among youngest girls and discussion about disliking needles/injections, risk of collapsing, etc.
- ◆ *Thousands of young women in the United States...*
- ◆ Most recognised and accepted this as reassurance on safety of the vaccination (tried and tested).
- ◆ But two ABC1 mums wanted more detail on this – why is it not millions? How has it been followed-up?
- ◆ Q&A information sheet provided sufficient additional information – and most importantly - reassurance for them.

Side effects

- ◆ One ABC1 dad remained concerned about the potential longer term side effects and would seek information beyond the Q&A sheet e.g. website suggested on sheet; US and Australian websites.
- ◆ Reference to *young women* in US and Australia – otherwise *girls* in leaflet – prompted a mum to ask their age.
- ◆ Preference by S2s to be referred to as *girls* and 16-17s as *young women* throughout.
- ◆ No clear preference among S3/S4s.

Missed your appointment

- ◆ Most accepted this.
- ◆ A few questioned why it was included in this leaflet.

Consent

- ◆ No comprehension or other issues for vast majority.
- ◆ Parental involvement in decision was not questioned – likely influenced in part by being in parent/daughter groups.
- ◆ Most parents of 12-13s fully expected largely to make the decision for their daughters.
- ◆ C2DE parents anticipated difficulty in encouraging daughter to have the injections if experience of the first one is particularly unpleasant.
- ◆ Daughters seemed to concur with these opinions.
- ◆ ABC1 dads (prompted by one dad only) discussed, and were uncomfortable with, suggestion that their 14-16 year old daughters could consent to the vaccination – to any medical procedure – without parental input.
- ◆ This will emerge as an issue for some parents – though the leaflet does not exacerbate it - and will need to be managed.

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.
- ◆ Oldest girls were also likely to seek additional information.
- ◆ Website is acceptable source of information.
- ◆ Request by C2DE parents (and a few individuals from across the sample) to provide Q&A information sheet with the leaflet – or at the very least have it available at schools.
- ◆ GP was also considered a reliable source of additional information and reassurance, especially for oldest girls.

Response to Q&A fact sheet

- ◆ All parents and at least one group from each age range of girls explored fact sheet.
- ◆ It answered outstanding questions on:
 - Types/names of cancer causing viruses.
 - Detail on numbers who have been given the vaccine and follow-up studies with web reference.
 - Rationale for vaccinating 12-13 year olds.
- ◆ But did not answer:
 - Will the vaccination still work on those who have been sexually active? For oldest girls especially.
 - Longer term side-effects. Suggests no answer is available on this yet.

Response to Q&A fact sheet

- ◆ Some girls saw contradiction in “as much as half the population will be infected at some time in their life” (p2) with the reference to “most of the population” in the leaflets.
- ◆ Introduced for one group of parents of 12-13s that HPV vaccination might only last five years...and be ineffective before these parents would expect (hope?) their daughters to have become sexually active.
- ◆ Led at least one C2DE mum to decide her daughter would not need the vaccination until a few years older.
- ◆ Encouraged other mums in this group to reconsider their earlier decision to consent.

Design/presentation - *Girl Thing*

- ◆ Preference among routine cohort for presentation of *Girl Thing*.
- ◆ Best and strong tonal balance of serious and informative with approachable and ‘new and relevant’:
 - NHS Scotland provenance on cover – as expected, trustworthy source, reliable/accurate information.
 - Clarity of purpose on cover i.e. *get my jab... to reduce risk of cancer...*
 - Design concept - writing, mirror, language – seen as friendly and well-targeted “like something we’d write”; unlike the norm for NHS/health leaflets; making it all seem less “scary”.
- ◆ Most 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.
- ◆ This is not necessary for most and risks undermining seriousness of content/decision about vaccination.

Design/presentation - *Girl Thing*

- ◆ Preference for foldout vs. booklet – seems shorter and less formal.
- ◆ No signalling problems.
- ◆ Welcomed the handwriting headlines – have signalling and tonal benefits.
- ◆ Legibility issue for a few over *Beating* at the top of each page.
- ◆ A few read *jab* as *job* and requested this be written more clearly.
- ◆ Appreciated highlighting *By having the vaccine* on page 2 of *Girl Thing* as a key piece of information.

Design/presentation - *Girl Thing*

- ◆ C2DE girls in older cohorts responded similarly positively towards *Girl Thing* – especially its informal, friendly tone.
- ◆ Lack of photo seemed to allow for broader target age range and included those in our sample aged up to 17.

But:

- ◆ ABC1 girls (and dads) in older groups rejected *Girl Thing* as “trying too hard” to appeal to teenagers viz girly design references.
- ◆ Tone for them was patronising and “juvenile”.
- ◆ “Cheeky”, offhand phrase *By the way, the vaccine won't protect against other sexually transmitted diseases...* reinforced perception that balance between serious and approachable had been undermined.
- ◆ Each of these ABC1 groups preferred *Pink*.

Design/presentation - *Pink*

Positives

- ◆ Clean, clear cover layout.
- ◆ Foldout leaflet.
- ◆ Larger writing (than *Girl Thing*).
- ◆ Orange page layout; suggests important info by being presented differently.
- ◆ Colours are appealing and pink targets girls without being 'too girly'.
- ◆ Photo = friendly, relaxed, nothing to worry about, these girls are supportive of one another.
- ◆ More conventional and serious than *Girl Thing* (for ABC1 older girls).

Design/presentation - *Pink*

Negatives

- ◆ More conventional and serious than *Girl Thing*.
- ◆ Girls are aged 15+.
- ◆ Girls look like models i.e. alienating (for C2DE girls especially).
- ◆ Gleaming smiles = better for a dentist leaflet.
- ◆ Dense writing and “boring” layout inside.
- ◆ NHS logo preferred on front vs. back.
- ◆ (Orange page usually read as p4.)

Design/presentation - *Pink*

- ◆ Alternative test photo - *Face to Face*:
 - More ‘realistic’ than *Original* and for some more appealing.
 - But again suggests 15 years or even older targeting.
 - Has lost relaxed tone and idea of supportive friends.
 - Suggested to a few that topic is bullying or mental health – “They are talking about things”.
 - Not a significant improvement over *Original*.
- ◆ Alternative test photo - *Young Girls*
- ◆ Most likely to be seen as very young – 12 years old at most.
- ◆ And for some these girls look ill at ease, tense.
- ◆ Again no improvement over *Original* for those who favour this design.

Design/presentation - *Leap*

- ◆ Least well received presentation across sample.
- ◆ Very conventional 'health information leaflet' colours, NHS logo and fonts on cover all present a serious and informative tone; overly so for some.
- ◆ Attempt to balance this with age appropriate appeal and approachability is not achieved.
- ◆ Largely because photos do not communicate as intended and are actively disliked:
 - Not well targeted - older than 12-13; usually late teens, sometimes older. Except "9 year old" on inside back cover which confuses.
 - Inappropriate actions e.g. leaping about, more like a jeans ad, going too far to be positive.

Design presentation - *Leap*

- ◆ Majority favoured fold-out over this booklet format.
- ◆ However, C2DE mums of 12-13s (and most of their daughters who were happy to be led by mum) preferred this over alternatives:
 - Reassured by familiar styling as a “health leaflet”.
 - Interpreted the girls as “typical, happy, lively teenagers” – though older than 12-13 years and to that extent not accurately targeted.

Recommendations

- ◆ Produce a single leaflet – *It's a Girl Thing* - for parents and girls in the S2 routine cohort.
- ◆ Implement suggested improvements e.g. to layout for ease of absorption and retention of info.
- ◆ Consider school talks to further explain new and sometimes complex ideas, especially to younger girls.
- ◆ Consider mass media campaign to familiarise and 'normalise' the vaccination as protecting against cervical cancer vs. an STI.
 - Should aim to undermine any potential misinterpretation of vaccine as 'for sexually active girls'.

Recommendations

- ◆ Prepare for issues that could prove to be barriers:
- ◆ Vaccine only lasts five years – wait until older if need a booster at 17 anyway. Most likely an issue for parents of S2s vs. older.
- ◆ Drop out after first injection in the course.
- ◆ Concerns that this will promote promiscuity – difficult to predict how widespread this might be but research suggests it will be a strongly held opinion by those who have it.

Recommendations

- ◆ Strength of rejection of *It's a Girl Thing* design/presentation by ABC1 girls (and parents) in the catch-up cohorts make it difficult to recommend it for these groups.
- ◆ However, *Pink* is not as approachable and well targeted as it could be for older C2DE girls.
- ◆ If either is selected for development, improvements to layout etc. as outlined earlier are recommended.
- ◆ Most importantly, leaflet must clarify implications for sexually active young women i.e. answer - will the vaccine still be effective?
- ◆ Preference in the sample of older catch-up cohort (i.e. two groups) is to have the vaccination through GP practice.
- ◆ However, delivery of the programme through schools (as appropriate) would likely also be acceptable.