

CervicalCheck Steering Committee
Weekly report to the Minister
6 July 2018

1. Overview

The Steering Committee met on Thursday 5 July. The meeting was co-chaired by the CMO, Dr Tony Holohan, and Ms Tracey Conroy, Assistant Secretary, Acute Hospitals Policy Division. The two patient representatives made a statement to the Committee setting out why they had agreed to join the Committee and what they hoped to see. This will be published as part of the meeting records.

In addition, a suggestion was made by Mr. Teap that a GP representative be added to the Committee. It was agreed that a GP representative would be a supportive addition and arrangements are to be put in place.

2. Update on support package and *ex gratia* payment

As previously advised, since the decision to establish the support package on 11th May, a team of specially designated Liaison Officers has been appointed to work with individuals and put in place the required supports. The HSE reported that Liaison Officers have held 157 face-to-face meetings to discuss their needs.

It is important to note that every individual's circumstances will be unique to them and thus the HSE has taken care to respect the wishes of the women and their families regarding the timing of contacts and subsequent meetings. Where meetings have not yet been held, this reflects the wishes of the individuals concerned either to meet at a future date that suits them or, in some instances not to take up the offer of support. With Liaison Officers engagement with women now established, it is not expected that numbers of meetings held will change significantly from week to week.

Further consideration is to be given to how best to ensure that affected women and families across the country are receiving clear and consistent information and support.

***Ex gratia* payment as recommended by Dr Scally**

Arrangements to make the ex-gratia payment of €2,000 to each of the women affected or, where a woman has died, to their next-of-kin are being coordinated through the Liaison Officers. The HSE reported that by the end of this week (6 July) it was expected that 176 payments would have been made. Remaining payments will be completed once individuals' banking details have been received.

Delivery of supports

- As reported on 6 July, the HSE had issued 445 new medical cards to women and family members or next-of-kin where the woman has, sadly, died. In addition, amendments have been made to the terms of existing medical cards or G.P visit cards in 87 cases to recategorise these as medical cards under the terms of the CervicalCheck support package.
- Alongside the provision of medical cards, primary care supports, including counselling, have been made available to those requesting them. This is very much a client-driven process and requests for supports will differ from individual to individual.
- A range of other health supports is being provided including in response to requests for physiotherapy, occupational therapy, dental, ophthalmic and nursing services among others.

- The Liaison Officers continue to interact on a daily basis via phone and email with clients. Interactions remain positive and good relations have been established in each Community Healthcare Organisation (CHO). There has been a fall-off in supports requested as other issues have taken priority for clients, including return of bank details (vendor forms) and engagement with the Scally Review. Engagements in and requests for supports would be expected to increase in the coming weeks.
- The Government decision of 11 May provided that where women had been prescribed a medicine by their treating clinician, any out-of-pocket costs would be met. This includes medicines not officially approved for reimbursement and any other non-standard therapies, once prescribed for the patient by their doctor.
- Arrangements are in place to reimburse a range of costs that the women and their families incur from 11 May including travel costs, childcare costs and medical appointment costs among others. These will be reimbursed upon receipt of claims from individuals.

Retrospective costs

- The Department is working with the HSE to gather information on the type and scale of costs that individuals have incurred, to enable a decision to be made on the most appropriate means of supporting people in this regard.

4. Release of records

A team has been put in place in CervicalCheck to deal with requests for records. The HSE has confirmed these are being processed within the required timeframes, other than in one or two cases where there are particular issues. This is in line with the Minister's expressed expectation that all patient information, including documents, files and audits related to patients, will be made available to patients or their representatives without delay, and that the provision of information will be streamlined to the fullest extent possible to avoid unnecessary bureaucracy.

- 118 legal requests have been received to date, of which 4 were received within the past week; 61 have been processed, of which 3 were within the past week
- 164 FOI or data access requests have been made and 129 responded to.

5. International Clinical Expert Panel Review

The International Clinical Expert Panel Review is being carried out under the auspices of the Royal College of Obstetricians and Gynaecologists (RCOG) with expertise also sourced through the British Society for Colposcopy and Cervical Pathology. The scope of the review includes all cases of invasive cervical cancer in Ireland since CervicalCheck was established, to include the 1,482 cases notified to CervicalCheck since then and a further 1,630 cases registered by the National Cancer Registry of Ireland which had not been notified to CervicalCheck. Women who developed cancer and who were screened by CervicalCheck will be identified and their screening histories will be examined.

The terms of reference and scope of the review have been agreed and the preparatory phase of the review is underway in line with the terms of reference. The Department of Health is committed to continuing to support and facilitate RCOG and the HSE in progressing this review as expediently as possible, and to do so in a way that ensures quality, comprehensiveness and integrity of the results. In that context, a number of meetings are planned for next week to continue progress.

6. Implementation of recommendations of the Scally Inquiry

The HSE has advised that it is committed to the implementation of the recommendations contained in the first progress report from Dr. Scally. An implementation plan outlining the key actions to be undertaken by the HSE to address the 4 recommendations contained in the report has been drafted.

The HSE has reported that initial arrangements for implementing the plan are already in place, including the establishment of working groups to coordinate the various streams of work and the appointment of a project manager to lead the development and implementation of the plan. The implementation team will throughout its work consult both with subject matter experts and with women who use the CervicalCheck screening services to ensure that all information is of high quality and user friendly.

7. Disclosure of newly received clinical audit results

Disclosure is now underway for the 12 women for whom clinical audit results have been newly received by CervicalCheck. These women are among the 1,482 whose diagnoses of cervical cancer were notified to CervicalCheck since 2008 and for whom CervicalCheck initiated the process of clinical audit. It can be noted again that, in April, when the Serious Incident Management Team undertook the task of identifying the number of women who should have been notified of discordant audit results, these women's audits were ongoing.

Contact for these 12 women with a Liaison Officer, in relation to the package of primary care supports, is being provided immediately following disclosure.

8. Introduction of HPV as the primary method of testing

The introduction of HPV testing as the primary screening mechanism for CervicalCheck, with cytology as a reflex test, will involve a reconfiguration of the laboratory work involved and will be subject to a tendering process for any work carried out outside the public sector. The HSE has advised that a Project Steering Group is in place for this work. The Department is continuing to engage with the HSE, within the Steering Committee, to ensure the switch to HPV testing progresses as quickly as possible.

The HSE has reported that lab activity, which had risen as a consequence both of out-of-cycle smears and increased uptake generally, has begun to diminish to more normal levels.

9. GP activity

Recognising concerns among women, any woman who has had a CervicalCheck smear test and where her GP feels she should have a further test as part of her reassurance can do so free of charge. While there is no defined end date for this arrangement, there is a need for review following the first three month period, as agreed with D/PER; an update in this regard will be provided to the Steering Committee at the next meeting.

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