

Ms Michelle Burrell
Acting Director
Council of Social Service of New South Wales
66 Albion St
Surry Hills NSW

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pls discuss

Dear Ms Burrell,

Electronic Health Record pilot

Thank you for your letter confirming the decisions made in discussions between NCOSS and the Healthelink team. Action has been taken on these issues as follows:

Review of the Community Language Privacy Notice to determine if the Privacy Notice can be provided as a link on the NSW Health Healthelink website for consumers to access.

The project team and the Department's legal branch has reviewed the Community Language Privacy Notice to determine whether this provides additional information that would be valuable to consumers. NSW Health has developed information brochures in the 16 most common community languages for the pilot areas. These describe how the program operates, including how to opt out and how to gain access to the record. The NSW Health Privacy statement is also available in 28 languages on the Health website. These two documents provide both specific information on the EHR and on privacy policy relevant to the health system. There is a risk that directing consumers to a third source of information may cause confusion.

The reference to the Privacy NSW - Office of the NSW Privacy Commissioner publication, 'Best practice guide - Privacy and people with decision-making disabilities' will be made available in the Healthelink training sessions to health care providers.

This reference has been included in training materials.

In the Healthelink training sessions provided to health care providers, it will be stressed by the trainers, and/or within the training program, that healthcare providers err on the side of giving capacity to consent to young people.

Project staff have been advised to err on the side of caution and give capacity. Existing decision making processes are used to determine whether a young person has capacity.

The Healthelink Team will review the Fact Sheet for Young People to ensure it clearly outlines to young people what information is made available (e.g. their home address) and who can access this information when the young person is enrolled in Healthelink.

The current version of the fact sheet outlines the type of clinical information that will be held on Healthelink, but does not specifically state that demographic information can be viewed in the record. The website does have an on-line demonstration of the system aimed at consumers that shows what information is held, including demographics. New versions of the brochures will indicate that demographic information is also held on the record.

The preferred is that homeless people will be able to use Healthelink. Currently they are not included in the pilot. The issue of how best to include homeless people will form part of the Healthelink evaluation.

Agreed. This will be included in the evaluation.

The Healthelink pilot evaluation will also consider:

- *the effectiveness of the information distributed to young people;*
- *whether the information kits were user friendly for young people;*
- *clinical perceptions of the reasons for young people opting out of Healthelink (in relation to GP's seeing this as an irrational response, or having an impact on their decision to assess capacity); and*
- *whether GPs felt they were able to determine the capacity of young people to consent to Healthelink.*

Agreed.

The Healthelink evaluation will seek further feedback on the Healthelink pilot, including the information resources, from the NSW Commission for Children and Young People's established focus groups

Agreed.

A community consultation strategy will be developed mid year prior to any state wide implementation of Healthelink. The plans for this strategy will be made available to community organisations and consumers for consultation.

Agreed.

The issue of blocking sensitive issues must be addressed beyond the Healthelink pilot and evaluation, with the implementation of further statewide clinical systems.

Agreed – this will be addressed in the evaluation and options for achieving this considered in the development of plans for broader implementation.

Reversal of capacity

Following subsequent discussions, the following process has been put in place:

Where a child has been deemed to have capacity and that decision is reversed by a clinician the following should apply.

1. The request to remove capacity should be escalated to the Service Centre Manager. All request for reversal will be investigated by the Service centre Manager. The request will not be automatically processed and cannot be processed until a two week period has elapsed from receipt of the request.
2. The Service Centre Manager should investigate the request and ensure that the clinician is aware of the consequences of processing the request. This should include:
 - a. Contacting the clinician to question why the request has been made
 - b. Establishing what, if any, action has been taken by the child to manage their own record, including establishing access themselves and removing associate access
 - c. Informing the clinician of the consequences of processing the request

In addition the Service Centre Manager may

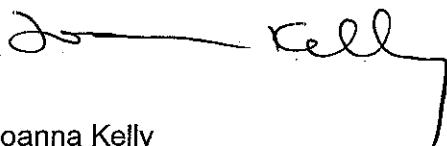
- a. Contact the young person
- b. Involve a paediatrician to provide advice
- c. Take other action as necessary to ensure that the request is properly considered.

The Service Centre tool will be used to track the progress of the investigation and record notes and the outcome.

3. The request cannot be processed until a two week period has elapsed from receipt of the request. This is to allow time for the decision to be reviewed and the issues to be considered by the parties concerned.

I hope this clarifies the action taken. I am happy to discuss this further if required and can be contacted on 02 991-9090 or email jkely@doh.health.nsw.gov.au. I would like to thank NCOSS for your interest and valuable input into this project.

Yours sincerely,

A handwritten signature in black ink that reads "Joanna Kelly". The signature is written in a cursive style with a long horizontal stroke extending to the left.

Joanna Kelly
Director, Portfolio Management

26/2/07