



Healthelink Issues

Issues of Capacity to Consent

The proposed policy states that a young person's GP will determine their capacity to consent:

1. How will young people and their families be informed about the choice for young people to be assessed for capacity to consent by their GP and what this means? In particular young people who may be below the age of 13 at the start of the trial. The reality is that many parents will receive the information kit but will not pass it on to the young person or the young person will not be interested in reading the Kit.
2. Will capacity be recorded anywhere in the Healthelink Record? For example, often young people do not go to the family GP when they are seeking assistance with some health issues. How will the new GP know that the person has already been assessed as having capacity?
3. How frequently will capacity be reviewed? An issue arises where the young person may have an episodic illness or a disability and they could be assessed as not having capacity at one visit to the GP but by the next visit this may have changed.
4. At the April EHR Steering Committee it was stated that all GPs in the Western Sydney trial would be trained in how to determine capacity to consent. However in regards to young people with disabilities often specialist training is needed as standard assessments may not be applicable. How will GPs be supported to have the knowledge in being able to determine capacity for this group of people?
5. Have any organisations that represent the needs and interests of young people been involved in designing the training for GPs to determine consent and complaints mechanisms particularly for young people who feel as if their capacity has been incorrectly assessed?
6. It was discussed at a previous EHR Committee meeting that for a minor to be considered "of capacity" a letter from the young person's GP would need to be presented to the Healthelink Administration staff before the process of removing access from the parents and to the young person could occur.
 - Have GPs been approached to determine whether or not they are happy to do this? What happens if they refuse?
 - How will the parent and young person be notified that access has been changed?
 - Will a copy of the GP letter determining capacity be sent to the young person and their parents/carer?
 - What happens if the young person's parent contests this decision?
 - How will the young person be supported when access to their Healthelink record is removed from their parent? It could be envisaged that in many

instances there will be a negative response from the parents when they can no longer access their child's record.

7. What happens in instances where the GP determines that the young person has capacity to consent but is worried that if they say this it could have negative impacts on:
 - The young person's home life (in many cultures it is not considered appropriate for the young person to be able to make these types of decisions and this could lead to difficulties for the young person)?
 - Their relationship with the young person's parents or carers?
8. What happens if there is no family GP? Many families use medical centres and see whichever GP is available at the time. This means that there is not an ongoing relationship with a particular GP who will then know and understand the young person's situation.
9. What policies will be in place in regards to young people that are either wards of the State or under some type of formal care? For example case workers who are supporting the child may also want to be able to access the young person's health records.
10. At this stage there is no ability for people to set who can and cannot access their health record. This means that any health practitioner involved in the trial will be able to access any child's records. This obviously raises concerns of child protection issues. While there is an audit trail and penalties for accessing a record inappropriately, this is all after the fact. How will issues of child protection be addressed and what safety mechanisms will be put in place?
11. How will access to a child's health record be managed where the parents are divorced?
 - Will both access and custodial parent be able to access the record?
 - What happens if the custodial parent wants to deny access to the access parent, especially in instances where relations between the two may be strained?
 - What happens if the young person wants to deny access to one parent but allow access to another?
12. In some situations a young person may not be determined as having capacity, or is under the age of 13, but they still do not want the GP to record information in their Healthlink record, especially if the issue is of a sensitive nature. For example:
 - Where a young person has a sexual health issue and their parent's religious beliefs or cultural background would mean that this young person could face difficulties in their home environment.
 - Where the young person may be facing abuse in the family and do not want to see their family GP

Will GPs have the ability to choose to 'not record' information in Healthlink? If not, how will this situation be managed?

13. Will the Healthlink Information Kit be made more accessible to young people and more 'child' friendly?

14. How will NSW Health ensure that young people and children have access to the kit and understand the information in the kit? Has consideration been given to asking schools to inform young people about the trial and handing out the kits? This could happen in a class session. Simply mailing the kit to the young person's home does not mean that the young person will see the kit.
15. How will young people who are homeless be able access the information kit, be informed of the trial and have access to their records? What happens in situations where the young person is 12 and does not want their parent to have access to their record?

Issues for Culturally and Linguistically Diverse Populations

1. At the Healthelink Steering Committee in April the Committee was informed that a poster, with information in various community languages, is included within the information pack. However some information packs that were given to Committee members did not include this information and therefore it is possible that information packs have been sent to people in the community without the poster. Is this being followed up?
2. It is good to see the website has links to information sheets in other languages, though it presumes that the person can read English to be able to find the information and is literate in their own language. However these information sheets are only 2 pages long, therefore the person is not getting the depth of information that is contained within the kit. Will some of the information in the kit, especially feedback forms and opt out forms be available in other languages?
3. Are the Interpreter Services that people are being referred to being informed about Healthelink and do they have a copy of the information kit so that they can inform people who contact them?
4. The Healthelink Record is only in English and it is acknowledged that it would be exceedingly difficult and the cost prohibitive to have the electronic record in other languages. This means that in order for a person who is not fluent in English to be able to understand their record they will have to have a family or community member, who is fluent in English, with them to read the file. This would not always be appropriate. It is also unlikely that the GP would have enough time to be able to sit down and go through the person's record with them. A phone interpreter service would not be able to assist. Will anything be put in place so that people will be able to go somewhere and have assistance with understanding their record i.e. a multicultural health service or community group, Refugee Health etc.?
5. Each year a number of refugee people are re-settled into Western Sydney and the North Coast, many speaking languages that are not currently in the community. How will the Healthelink project monitor the changing language needs of the community to ensure that all people remain informed and able to consent to their participation in the trials?

General Issues

The Healthelink trials have been established in areas and with age cohorts that are frequent users of health services. The reasons for this are obvious and will provide a good overview of the effectiveness of the system. However the issues for people aged between

15 and 50 are very different. This group is more aware of privacy issues and have more concerns about how their health information is accessed and used and who accesses and uses this information. They are also more likely to have sensitive health information that they do not want recorded, shared or available to all health practitioners. How will NSW Health determine the attitudes of this group to Healthelink and address their needs and issues?