Submission No 0006

INQUIRY INTO OFF-PROTOCOL PRESCRIBING OF CHEMOTHERAPY IN NSW

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Inquiry into off-protocol prescribing of chemotherapy in New South Wales

Terms of reference

1. That a select committee be established to inquire into and report on off-protocol prescribing of chemotherapy in NSW including at St Vincent's Hospital, St George Hospital, Sutherland Hospital, Macquarie University Hospital and clinics at Orange and Bathurst, and in particular:

   (a) the efficacy of electronic prescribing systems, and their capacity to stop or limit off- protocol prescribing of chemotherapy,

   (b) the value of a potential new patient information sheet on dose adjustment for patients and caregivers information,

Potentially this would be helpful to patients/carers but I do not see it working for the following reasons:

Point One

Patient do not know recommended doses and if they google they can be miss informed, if they take it to a GP they are not always going to know the correct doses and will say that the Oncologist is the specialist and will go with what the recommend.

On the occasion that the patient or GP question the oncologist I feel they say whatever to convince you that they are doing the right thing. When you are told that you could be dead in weeks if you do not start treatment and it can take up to nine weeks to get into see a specialist you do not have time for a second opinion.

If you do go somewhere else for a second opinion, they will refer to the first specialist and give you the same answer.

On occasions that we attended the same specialist quite often we were told conflicting information.

Point Two

The doctors not doing the right thing will simply not provide the information sheets to patients/carers and therefore the patient/carer would be none the wiser.

This happened to my husband – the specialist asked many questions about my husband and his business and then determined that my husband could afford the operation and never provided us with the information about been admitted as a public/private/self-funded patient. The specialist never linked us up with a social worker until after the operation and we had to pay for operation, even when it was lifesaving operations and not elective surgery.

Other patients were provided with the information sheet about public/private/self-funding and they were linked with a social worker who explained everything and did not have to pay.

Point Three

Medical Practitioners forget they are dealing with people's lives and do not allow enough time for appointments, therefore patient/carers do not have enough time to ask questions most doctors rush

you in and tell you what they are going to do. If you question the doctor and become very upset and let you know that they are the expert and to trust them.

This is not always the fault of the medical practitioner, they are under extreme pressure due to an aging population and other community related health issues. Also some medical practitioners at a senior level have dual roles and their time is used in multiple capacities. Example: A Doctor is a consulting surgeon and also the Director of Cancer Services and I am sure excellent in both roles, however this is to the determinant of his patients as his consulting time is reduced.

Suggested Solution

Each medical practitioner should follow the protocol already in place in, the committee need to look at how to ensure this happens. The medical practitioners need to be held more accountable.

Engage the social workers to meet with all new patients, if the social worker see any serious issues they should be able to take serious issues to corporate governance to be assessed.

Or a hotline with NSW health similar to "crime stoppers", that anything can be reported from to do with patient care. All associated parties are able to use the hotline, patients, carers and all medical practitioners. This way all serious issues can be addressed and data is collected and issues will become apparent sooner.

Central recordkeeping processing unit with NSW health – where a customer service person can contact a patient/carer ask questions, at your appointment did your doctor provide you an information sheet on and other vital questions.

Senior medical practitioner may need more support, more registrar or intern or administration assistance. In the VET industry each workplace trainer has a quota of 100 students, with a 100 students you have one full time admin support person, and then for an extra 20 students you have get an assessor 15 hours to assist with marking. I know that a lot of the medical practitioners run their own practices and are not under the governance of the hospital. But maybe NSW health need to set guideline similar if not already in place.

(c)	the process and systems around informed consent for all medical interventions, including chemotherapy,

I feel this would not work for the same reason as above – medical practitioners will briefly explain this is what is going to happen and now please sign the consent form and we can get started. Patients are vulnerable, scared and they trust the medical practitioners, I feel that this will only cover the medical practitioner and the patient will have no come back as "they consented". I totally disagree with this action.

Suggested Solution

As above

(d)	the capacity of the NSW Health system to have all notifiable cancer patients in New South Wales overseen by a Multidisciplinary Cancer Care Teams, and if this may prevent off-protocol prescribing,

This was happening at St Vincent's, every Tuesday the Head and Neck team met at Kinghorn Centre at 11.00am. During the meeting the Director of Head and Neck, the interns and registrars

would examine each new patient, this examination was streamed live to the multidisciplinary Cancer Care Team. Collaboratively the team would discuss the best options for the patient and this was then relayed to the patient.

As far as I know the meetings included the following medical personnel;

- Director of Neck and Neck
- Surgeons
- Oncologists
- Oncology Radiologists
- Medical Registrars and Interns
- Social Workers
- Dietitians
- Speech pathologist

After the airing of the situation on ABC 7.30 Report, I spoke with Dr Richard Gallagher about the whole team knowing about the dosing quantity. I said that the surgeons must know of the dose that Dr Grygiel was giving and he denied that a surgeon would know the dose, he said that he does not ask about doses as the oncologist is the specialist. However now at Royal North Shore they provide the GP with a letter after each of Ken's treatment and is talks about 25mg of this and 50mg of other. I think Dr Gallagher's explanation was a weak excuse and a case of passing the buck.

Therefore I do not see this point working – senior medical practitioner's manipulate and intimidate other personnel who are too scared to speak up.

As far as I know the protocol is the registrar checks the patients' blood results and then order the chemotherapy from pharmacy where a script would have changed hands at least twice. Then before hooking up the chemotherapy two nurses check the package and check the patient and sign the register. Therefore at least four hospital personnel are aware of the dose. Or if they did say anything what happened?

Suggested Solution

Continue to have multidisciplinary cancer care team meetings, but the senior medical practitioners need to be held more accountable for their actions.

I do not know much about the medical legislation and medical practitioner employment contracts but I feel that legislation and employment contract should be like the workplace health and safety legislation and each breach holds a point's value relating back to a monetary value.

(e)	St Vincent's Hospital capability to comply with relevant NSW Health Policy Directives and Guidelines, particularly Open Disclosure Policy (PD2014_028) and Incident Management Policy (PD2014_004),

Point One

St Vincent's Hospital clearly did not comply with the above, "Open Disclosure Policy" was not adhered to. I feel that most medical practitioners do not adhere to the "Open Disclosure Policy",

Actual Fact regarding Open Disclosure

After seeing the ABC's 7.30 Report – we had an appointment with Doctor Grygiel the following morning at 9.00am. On arrival we booked in at reception and then the registrar took us into the consulting rooms, we had the consultation and no Dr Grygiel – our consultation took a very long time as I kept arguing with her as we didn't believe that my husband was in remission and I kept question her, she said "go home and forget about the cancer and starting living our lives". But only two weeks before the oncologist in Port Macquarie gave us the news that the chemo had not worked and that was why he went back to see Dr Grygiel. Then she is saying my husband was ok??

Finally when she told us to go home – I brought up about Dr Grygiel under dosing and that we saw it on TV, she replied that she only found out about it at 5.00am that morning and didn't know much. I asked if she could get someone that did know something, she left the room for about 20 mins and returned with a Dr and he said that yes my husband is one of the patients and that it appears that he only received a third of what he should have.

Dr said "well as least you got some chemo, some is better than none".
As the doctors were not forth coming with information, I had to ask what that means for my husband and what happens from now. Again we were told "just go home and do a routine check-up in 3 months". During this time I had become hysterical and was clearly very distressed, they wish us all the best and showed us the door. Never were we asked if they could get us anything, never did they get a social worker to talk with us.

Suggested Solution

Work needs to be done with the culture of the senior medical practitioner to ensure that they operate

in an ethical manner and respectful manner.

They also need a lesson in communication with patients, we are humans not numbers
Again for "Open Disclosure" to happen when an incident has occurred the medical practitioner needs time with patients to explain issues and the contingency plan. During these type of meetings I feel a social worker or corporate governance personnel needs to be in attendance.

(f)	the NSW Health Code of Conduct and specific programmes within NSW Health and St Vincent's Hospital, in relation to staff raising concerns about the practice of clinicians, and other breaches of the Code of Conduct.

I cannot contribute to this point as I am unsure of "Code of Conduct", but I believe that nurses from the Kinghorn Centre did raise questions and reports their concerns but nothing was done.

Overall Comment:

I hate to waste tax payer's money and would have thought the inquiries so far would have found out more. What was reported and recommended was nothing that we didn't already know.

Ideally I would like to see a royal commission not only into the under dosing but into unethical behaviour of senior medication practitioners in NSW health system.

But if they could not prove anything with Dr Jayant Patel after four years – the same will happen. When doctors talk to a patient they use all medical terms and the patient has no idea what is been said and it all sounds impressive. All medical practitioners should be contextualising the information so patients full understand the context of the information.

However knowing the outcomes of the Dr Jayant Patel case I am not confident anything would happen apart from wasting years of people's lives and using tax payer's money. The money could be spent to set up an audit team and randomly audits and checks over medical practitioners.

All meetings with doctors should be recorded, a copy of the recording should be given to the patients and also archived with NSW health. At any time patient medical records should be reviewed by NSW health. Spot audits should be conducted by an independent body.

There are protocol's in place but the problem is that are not been followed and there is a culture of cover up and doing what they like at a senior level.

The culture of the senior practitioner needs to change and they need to be held accountable, but unfortunately issues are not discovered until the damage has been done.

I would like to see enforceable breaches in the legislation and breaches also holding a monetary penalty.