

Health IT and multidisciplinary community healthcare: an examination of the knowledge and practice of nurses working in the community concerning electronic patient records, access and privacy

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#### **Abstract**

#### Aim

To explore the views, expectations, practice and attitudes of registered nurses and nurse leaders working in community and primary health care settings concerning patient privacy, mobile devices and data storage platforms.

#### Method

A mixed methods approach including an environmental scan and individual, paired and focus group interviews with nurses working in the community (22), professional nurse advisers (6), medico-legal advisers (2) and nurse leaders and managers (6) was used. Data were analysed using a general inductive approach (Thomas, 2006). Ethics approval was gained from the Victoria University of Wellington Human Ethics Committee.

#### Results

A review of nursing regulations, guidelines, policies and procedures revealed privacy/confidentiality of patient information to be viewed as vitally important. Although many principles and issues related to changing from paper-based notes to electronic ways of working were adequately covered by existing documents, a need for clearer guidelines on privacy in the use of electronic patient notes for exemplar writing and on telehealth in general was identified. In all settings, nurses had excellent understanding of issues associated with privacy, consent and the use of health IT, however practical barriers led to less secure digital ways of working, or less effective use of available technology. With nurse input into design, and better targeted, individualised education nurses could use health IT more effectively.

#### Conclusion

Nurses have good understanding of issues associated with privacy and electronic records however new summary documents and advice regarding the use of records for study or reflective practice were identified as being required. These have been developed and will be disseminated. IT designers need to work with nurses to ensure systems and processes adequately meet practice needs.

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# **Background**

The New Zealand Nurses Organisation (NZNO) is New Zealand's largest professional and industrial organisation representing the interests of over 47,000 nurses, midwives, students of nursing, kaiāwhina and other health professionals. Over 38,000 of these members are registered or enrolled nurses, nurse practitioners or students of nursing. NZNO has a strong interest in supporting nurses to practise safely and to this end undertakes a range of professional activities designed to support nurses. These activities include providing a range of professional guidance documents for nurses, independent and collaborative research into nursing workforce issues and policy advice. This project arose out of a need to examine issues surrounding the use of health information technology by nurses.

There have been many recent developments in health information technology and its increasing use by multidisciplinary teams. These include the development of systems by which patient records and results are stored and accessed in digital formats throughout the health system (Health IT Board, 2014). Personal health information is increasingly available (with appropriate access) across disciplines and health care organisations. Settings can include: homes; primary care; secondary care; residential care; and pharmacies. Disciplines include: doctors; nurses; allied health professionals; and pharmacists. Devices such as lap tops, tablets, and smart phones which have functions such as internet access, bluetooth, video and sound recording capacity may now (or shortly) be taken out and used in the community, and within people's homes. Considerable input has been made at the highest professional levels regarding patient record access, data security and the privacy safeguards required of the new systems. This includes the development of guidelines. However, how this input is understood or acted on by nurses working directly with patients in the community is not known.

While improved communication and easier access to patient records may be clinically useful (particularly in primary care and the community), the knowledge and understanding of nurses regarding the issues and practicalities surrounding

privacy is unknown. An initial literature review has revealed little relevant, recent research on this topic in New Zealand, though acknowledgement that practitioner acceptance and understanding will be crucial to implementation was identified by health informatics researchers at Massey University (Hare, Whitworth, & Deek, 2006). International research has also identified that user acceptance of health IT is crucial to successful implementation (O'Mahony, Wright, Yogeswaran & Govere, 2014). Concern about lack of detailed understanding of new health IT systems and safeguards, perceptions of the potential to be involved in breaches of privacy (with attendant consequences for employment and professional regulation), and concern regarding patient acceptance of IT based health records are significant factors yet the degree to which these have been addressed in community health settings in New Zealand is unknown. It is essential staff are involved and supported to implement these changes and have their fears and concerns identified and addressed (Swartz, 2012). Community settings, where interfaces between primary, secondary, and residential care, and between multidisciplinary health care teams including pharmacists and allied health professionals have great potential to benefit patients and increase efficiency; but also may have the greatest potential for issues of privacy to cause confusion, distress or even harm. While the overwhelming proportion of healthcare data breaches in the US in 2013 (84.9%) involved theft and hacking, a not insubstantial 10.6% were accounted for by inappropriate access, loss or improper disposal (Infosec Institute, 2014). In New Zealand a recent case brought by the Professional Conduct Committee of the Nursing Council of New Zealand to the Health Practitioner Disciplinary Tribunal described inappropriate access or viewing by a nurse of electronic health records of patients and colleagues (New Zealand Health Practitioners Disciplinary Tribunal, 2015). The nurse was found guilty and censured.

For public acceptance too, it is important that health professionals understand and can communicate the issues surrounding access to e-health records simply to patients. In addition to concerns the public may have about privacy, professional concerns regarding data integrity (cloning content or restrictive "pick lists") and data availability (platform instability, outages, and password failures, particularly in

emergency situations) also lead to concerns from clinicians about "paperless" systems.

#### Aim

The aim of this study was to explore the views, expectations, practice and attitudes of registered nurses and nurse leaders working in community/primary health care settings concerning the confidentiality and privacy issues surrounding access to electronic patient records and notes – especially those concerning the use of mobile devices and data storage platforms.

# **Method**

This descriptive study used a mixed methods approach. An initial environmental scan examined existing policies, guidelines and information relating to nursing and electronic patient records. Following ethical approval, purposive sampling was undertaken to recruit nurses working in a range of organisations at different stages of the introduction and use of electronic patient records and/or mobile technology. Individual, paired and focus groups were undertaken with nurses working in the community and nurse leaders/managers exploring the issues and understandings surrounding the patient confidentiality aspects of health IT. Data were recorded, transcribed and analysed descriptively using a general inductive approach seeking common themes and perspectives (Thomas, 2006).

# **Ethical approval**

Ethical Approval was obtained from the Victoria University Human Ethics Committee (Ethics Approval # 22444, 19 November 2015).

# **Acknowledgements**

The authors wish to acknowledge the Office of the Privacy Commissioner, New Zealand for financial support for the project. We would also like to acknowledge the senior nursing management support and the interest and commitment of those nurses who contributed their time and experiences to the project.

# Results

# **Review of existing materials**

The Nursing Council of New Zealand (Nursing Council) Code of Conduct (2012) and the New Zealand Nurses Organisation (NZNO) Code of Ethics (2010) are both explicit about the absolute professional duty to maintain patient confidentiality, and about the need to act within the Privacy Act at all times. Specifically, in response to societal changes, NZNO in collaboration with Nurse Educators in the Tertiary Sector (NETS) and the Nursing Council have both recently developed Social Media Guidance which again highlights both patient privacy (including the use of photos) and professional boundaries (NZNO & NETS, 2012; Nursing Council, 2013). Employers too have policies and procedures safeguarding access to medical records, and standards of operation of health IT. Breaches of these protocols are viewed seriously – including inappropriate access or disclosure being classified as gross misconduct which can potentially lead to dismissal.

Nurse Executives of New Zealand (NENZ) produced a position statement on Health IT in March 2015 which outlined key considerations for nurses when using Health IT. The document focuses on nursing practice, in particular obligations to ensure that ethical, safe and therapeutic relationships are not compromised by an electronic delivery medium. They also called for nursing to be fully involved, and to inform and evaluate the development and delivery of new Health IT initiatives.

NZNO itself does not currently have guidelines specifically about the use of health IT systems and electronic patient records, though the standards required for nurse documentation in patient records apply whether paper-based or electronic (NZNO does provide guidance on best practice in documentation). A draft NZNO position statement on Health IT and new guidelines on use of patient records in reflective writing (informed by this project) have been produced, and are appended to this report. Nurses from other jurisdictions (notably Canada and some states in the US) have also produced guidelines in response to the introduction of electronic patient records, and NZNO will continue to scan these for changes to international best

practice advice and where appropriate will update our documents in response where we discover developments in New Zealand require this.

An examination of the material available from the Health Information New Zealand (HINZ) web site shows that the national health IT system is advanced and rapidly developing. Further, it is hoped that soon there will be an electronic health record for every registered New Zealander, with layered, protected access to records enabling appropriate sharing between different health providers, laboratories, diagnostics, funders and pharmacists. Complex systems have been devised to allow access only to those parts of records that are clinically required, for highly secure access clearance and for the many different systems in operation in general practice and DHB settings to interface seamlessly. The National Health IT Board has several high level work streams, one of which focuses on understanding the needs of clinicians, and another, patients. Information sharing is one aspect, others include patient portals, health IT, e-referrals and e-discharges. Within services, additional facility exists for clinical decision support (algorithms and clinical information) and for medicine management information.

The HISO10013:2015 HL7 standards for interoperability have been endorsed for use in the NZ health and disability sector, and were revised in 2015 to reflect advances in health information technology and the increased requirements for the secure electronic exchange of information between healthcare providers.

# Interviews and focus groups

Interviews and focus groups with 36 informants were conducted. The main findings from each group follow.

Nurse leaders (4)

Four senior nurse leaders (one involved with the Health IT board) were interviewed about the privacy elements of health e-records. All were unequivocal about the benefit to patients and clinicians of electronic records. Advantages cited included:

- > Essential clinical information being available as needed meaning changes to medication or condition and even patient location were available to all members of Multi-Disciplinary Teams (MDT) as needed. Hospital discharge tracking and follow up were seen as being enhanced. For example, this avoided nurses visiting patients at home, only to find they had been readmitted to hospital. It was particularly helpful in the palliative care context, where rapid changes can occur and good coordination and continuity of care are essential.
- > The records of highly mobile and vulnerable families and children can be tracked around the country if needed, ensuring continuity and additional opportunities to protect at-risk children.
- > The integrity and auditability of the patient record have undoubtedly improved record keeping, facilitated audit and allowed more rapid managerial responses to errors (including systematic errors). This was also particularly helpful in the investigation and resolution of complaints.
- > All were confident that the privacy / access / data security aspects of the records systems had been adequately designed.
- > There are many different systems and devices in use in New Zealand. These range from iPads to phones and other Android tablets. Where these are in use, policies and procedures, including GPS tracking of lost devices were in place. Having said that, as these devices were portals rather than repositories of patient data, are password protected and have automatic time-out settings, no privacy risk as such exists. Screen size on mobile phones is too small for utility.
- > It was noted that it is common practice to access the relevant clinical information in preparation for a visit, to continue to make paper notes in the presence of patients, and to transfer this to the IT system on return to base, followed by shredding of notes as appropriate. This dual-entry process was time consuming and acknowledged as frustrating by participants.
- > Initial barriers to the adoption of technology can be addressed by appropriate training. In some cases this included basic computer literacy, and addressing perceptions that computers (and hand held devices) cause barriers between

- nurses and patients, or change the nurse/patient relationship and communication.
- > The importance of investing appropriately in both systems designed for the needs of each service (with MDT input) and in staff training and support were emphasised.
- > An interesting question was raised about the legal status of health data (especially that related to diagnostics) held by offshore providers, or of cloud storage / back up of data. This also raises questions regarding the confidentiality of patient information held offshore where New Zealand jurisdiction does not extend.
- No nurse leaders were aware of any patient complaints related to privacy and electronic health records as such. This contrasted with recent high profile privacy breaches from ACC and WINZ mostly related to sending information (either electronically or on paper) to the wrong individuals.

#### Professional nursing advisors (6)

Six NZNO professional nursing advisors took part in a guided discussion. The main concerns that emerged are listed below.

- > Due to technical issues, including access to appropriate technology, many nurses are placed in the position of operating work-arounds in order to meet their clinical obligations. In some cases, these may lead to a potential risk of privacy breach. An example of this was a practice of printing patient labels from the system (which can contain large amounts of detail) and using them as place markers in visit diaries. Nurses should be reminded that these pose a risk for breaches if lost or mislaid, and that they must be destroyed once their use had passed.
- > There was a consensus that privacy was safer with the use of tablets and phones, as these were in effect a password-protected portal to notes, rather than copies of notes themselves. The days of notes being left in district nurses' cars between patient visits are hopefully over. (\* see later)

- > Questions were raised about whether patients fully understood and consented to the use of their notes for competency or disciplinary purposes, and for teaching and audit.
- > It was reported that some nurses re-visited the notes of patients they had previously cared for in order to document their own professional practice: and it was identified that better understanding of issues surrounding privacy and confidentiality in this situation was required.
- Nurses are largely widely aware that within DHBs especially, every access of notes (paper or electronic) was auditable, and that flags could be generated and consequences ensue following inappropriate access.
- > Incidents had arisen where nurses had been asked to justify their access of patients not apparently under their care. (Often this was an administrative consequence of nurses being moved from ward to ward, and on examination their access had been found to be appropriate.)
- After an initial few high profile breaches, DHBs had increased awareness and instigated on-screen warning messages before access, so incidents of privacy breaches resulting in discipline were declining.
- > It was less clear for some that nurses working in residential or primary care were similarly aware, or their systems as auditable. Further information on the situation in aged and residential care is found later in the document.
- > There are issues with temporary logins in some settings, especially for students on placement, though appropriate supervision appeared to be in place, and students sign confidentiality agreements.
- There can also be issues with Word documents such as discharge summaries or letters. These are sometimes temporarily stored in unsecured file structures on shared drives and hard drives during their preparation, with consequences for security.

#### Nursing medico-legal lawyers (2)

Two NZNO medico-legal lawyers took part in a guided discussion. The main concerns emerging are listed below.

- > While the nature of electronic records facilitate tracking of distribution and access, there can be concerns about the legal status of access to and storage of patient notes (within the Privacy Act) in the case of them being required for Health and Disability inquiries, Nursing Council competency reviews and nurse employment disciplinary resolution. The medico-legal lawyers recommend that such uses are subject to OIA requests via DHB or PHO processes, along with robust security processes as for all legal records are in place.
- > The lawyers reported that only persistent or malicious breaches of privacy were now appearing through the appropriate processes. The lawyers believed this was due to better training and awareness of the consequences of breaches resulting in reduced incidence.

#### Nursing manager

One experienced RN manager described her experience working for an aged care provider.

- > Private companies are responsible for commissioning and purchasing their own IT systems and IT support. These appear to have very variable system controls, and compatibility; sharing and reporting requirements can differ widely.
- > Productivity, and accuracy / accountability around prescribing in particular have driven IT use and innovation in aged care. There was a feeling it improved accuracy, enabled audit, facilitated nurse handover (especially with agency staff) and also speed of communication.
- > They had access to InterRAI, Medtech, MediMap and pathology results. Recent (within the last 3-5 years) changes in policies and processes, such as employment contracts with confidentiality agreements, had really tightened up on privacy.

- She still felt anyone could look at any paper records within house, and no one would be any the wiser, unlike the stringent controls in place on Medtech access.
- > Other aspects of IT in the care home environment of concern regarding privacy includes sending material to non-secure printers and FAX machines.
- > E-records are helpful in the investigation of complaints.
- > E-records eliminate the problems of reading poor handwriting.
- > They could also help improve the completeness of records, with mandatory fields specified.
- Very few aids such as mobiles, tablets etc are provided for staff. Nursing staff sometimes e-mailed patients (from work), and doctors frequently communicate with the home and other agencies (eg pathology, pharmacy) by what the informant felt were fairly non-secure e-mail systems.
- Some concerns that family of patients can and do abuse electronic and social media – by posting complaints and photos for example, that a care home has no redress over.
- Issues identified include a high turnover of MDT members (especially GPs and pharmacists) and that overseas trained staff can have patchy knowledge of NZ systems.
- > Privacy should work both ways to protect nurses too.

#### Nurse Manager; Community

One practice manager (RN) talked about her experience of IT as a manager.

- > Electronic patient records, along with guided decision support and dashboard prompting has helped with targets and funding but still relies on staff filling in the relevant boxes.
- > Policies are mainly available on line (she questioned whether people read them, or just tick the box to confirm they have read them). There were issues identified with policies being in one system and patient records being in another requiring multiple passwords to access the various systems. Systems with policies were less frequently used and therefore passwords more likely to

- be forgotten or shared with others meaning policies were more likely to go unread or not accessed when they perhaps should be.
- > 3 year update training on privacy specifically is in place in their organisation.
- > There has been a lot of awareness raising and training about the privacy aspects of electronic shared records.
- > Privacy breaches are spotted, investigated, and historically this has led to a severe warning.
- > Rural nurses in particular need to be scrupulous about their boundaries and confidentiality when they know the whole family for example.
- > Confidentiality in shared office space is an issue. Even with headsets patient information can be heard by others in the room.
- > There are also issues with regular changes and locum GPs not knowing or using the systems.
- > IT is enabling a much more joined up patient journey. Specialist nurses have access to palliative patient notes and to GPs via email for urgent consults.
- > Some copy and pasting of email conversations into the patients electronic notes (as currently) will be facilitated by the ability to directly write into notes.
- > Privacy concerns and lack of communication around mental health services (not currently joined into the system, and with different access due to the additional sensitivity around mental health) mean that clinicians don't have the information they need for mental health patients coming into GP or ED.

#### Practice nurses

Eight practice nurses from 3, largely rural, settings took part in interviews and focus groups.

- > Practice nurses have access to Health Connect South, lab reports and hospital discharge letters
- > No IT access to Mental Health notes (except in an emergency, and access is tracked) though GPs can access those. The CAT teams (Community mental health outreach) sometimes FAX through notes acknowledged as potentially far less secure. Although FAX is less secure, it can help when phone lines are

- busy and for example rest homes want to know a message can be received. Pre-programming of FAX numbers can avoid inadvertent breaches.
- > In small communities, inter-professional communication is easier as people have known and worked together for many years, and voices are recognised.
- > Conversely, privacy can be harder to maintain in small rural communities.
- Direct electronic communication with patients (texting to remind people of appointments, or being able to get straight through rather than risk leaving messages on general answerphones) is helpful for both privacy and immediacy.
- > While some doctors allow patients to directly email them, there are issues with patients assuming because they have sent something, that this will have been received, seen and acted on, when for example, a GP could be on leave.
- > Some were unsure of the legitimacy of accessing their own notes

#### Nurses working in the community

- 14 District Nurses (DN) (including 2 student nurses on placement with a DN team) from three settings in both the North and South Islands took part in focus groups.
- > (South Island) DN have access to Health Connect South and Health One (for those enrolled in Health One, patients can opt to allow the DN team to have access to pharmacy notes). DN also have read-only access to MedTech. Health One also allows Pharmacists, Plunket nurses, and staff in A&E to see limited information about patients when needed.
- North Island) DN had access to the discharge summaries and test results from the DHB MAP (Medical Application program), also to PAL Care (Palliative Care) portal to access Hospice notes, and to some GP records. There was some evidence of sharing MAP notes across DHBs, for example for specialist services provided at geographically linked DHBs.
- > Some systems allowed DN to write into notes (e.g. PAL Care), while others (MAP) only allowed DN to read discharge summaries and other notes. Inability

- to have fully integrated / read / write access to all notes was apparent: "the potential is nowhere near achieved".
- > There are issues with expired log-ins and lack of confidence using systems and processes along with IT failing intermittently leading not to privacy risks, but to missing the potential of IT to enhance patient care and coordination. "Well actually I stopped going to MedTech now although I love the programme and did use it for many years but it is just another password to remember and it expires like if you don't go into it every week just about and so then you've got to go through the process".
- Most notes for DN are still hard copy so teams like palliative care nurses out of hours have to access and consult the paper files. Audit trails are less effective with hard files.
- > Trials some years ago with hand held devices using a programme called i-SOFT were experienced as very cumbersome to use, were thought of more as workload management and funding / reporting tools than patient management tools, and created more, not less work for nurses.
- > Some issues with inability to share notes between district nursing teams and (for example) A&E, due to the persistence of hard files.
- > DN patient files at all sites we visited are hard copy, and contain only the DN notes. Other allied health professionals in the DN outreach team (e.g. occupational therapy, speech therapy, social work) also all have their own hard copy notes. Notes can be requested and shared during multidisciplinary team working as appropriate, all notes are booked out and signed for by the central records system. There can be problems though sometimes locating notes if they are stuck in peoples in-trays for example. (Notes are not so much "lost" as "not locatable").
- Sood liaison between DN and GP practice nurses via shared meetings combined with small populations mean that the potential loss of coordination is less problematic than it would be in much larger, more anonymous settings.
- > There had been an incident where a patients notes had been left at their house by mistake, and they (the patient) had read them. Comment was made that electronic notes would reduce this risk.

- Some DN teams had real issues with clinically relevant photographs (eg wound progress) not being able to be loaded into patient electronic notes: this will have to be fixed if paper notes are to be phased out. Other DN teams had dedicated digital cameras and cloud storage of clinical photos such as wounds and progress with healing.
- > Applications (such as medicine management, or leg ulcer treatment pathways) that are available on smart phones and which would be helpful clinically, are blocked due to issues with internet and the cost of data access in one DHB, so most nurses who could benefit from these tools are prevented from doing so.
- Less than ideal work-arounds concerning the use of emails, faxes, print-outs are frequently tried by nurses. Email can be a surer and quicker form of communication than trying to get through on the phone, leaving messages or getting someone to ring back while the nurse is available. Some of these might potentially risk privacy breaches. Assumptions of internet and cell phone coverage don't hold in rural areas.
- > Communications between health and other government agencies, such as ACC, or between private practices, are not considered secure, so faxes again are the default method. "things sit on the fax and different clinicians don't necessarily know it's been faxed through at that time so they're not waiting there for it to come and it's got patient information on it"
- > There was good understanding of the different levels of sensitivity of health information, and more sensitive areas triggered more secure transmission of information.
- > There are situations where nurse safety (for example home visits / alcohol / drugs / violence) and patient confidentiality what is in the notes might appear in conflict, especially if a patient or a patient plus their partner were to see their notes inappropriately.
- > Some DN had been provided with G4-enabled iPads on which to access MAP. The use of Apple technology restricted compatibility with other DHB systems, even letter writing and storage.
- > Different DHBs have different locked notes areas: for example in one place it was sexual health notes, another it was mental health (apart from discharge

- notes) or psycho-geriatric assessments, while at a third, it was access to the specialist human genetics notes.
- > The effectiveness of IT support did not always appear to match the needs of the nurses.
- > There was some lack of clarity about the access to patient records that can be seen by the IT helpdesks – as remote access by the IT people was required to problem solve, if those pages were open, they could be viewed. However, IT people also sign confidentiality agreements. More communication between departments to reassure nurses of this could be helpful.
- Newer changes such as remote log ins from personal computers at home were acknowledged as potential sources of privacy breaches, though there was acknowledgement that not leaving screens unlocked and unattended was important.
- > Perhaps because of the age group of patients, no DN reported patients asking to see their own notes or expressing any concern about electronic records. All were aware of the policies surrounding patient's access to their notes. Most were aware of (though not all understood or agreed with) policies relating to looking up their own notes in the system.
- > National electronic records systems would address the issues caused by mobile patient populations and out of area access to GP practices.

# **Discussion**

# **Privacy**

It was apparent in all settings, and at all levels within the services and organisations that were part of this small study, that nurses understand and adhere to high levels of protection of patient privacy. We believe that any *privacy* concerns about electronic patient records, and their use by nurses in the community are unfounded.

Nurses were aware of potential risks related to e-mails, mobile phones, answer phones and FAX machines. They also were aware of the rapidly changing use of social media, of (patients or nurses) uploading photographs from cameras, and the risks these pose to both patient confidentiality and nurse professionalism. They trusted those charged with protecting the systems against malicious or fraudulent IT security breaches, and appeared well briefed on good computer security procedures in the workplace.

Further discussion, direction and guidance is required concerning access to one's own notes and records in some settings, and perhaps clearer understanding of the safeguards needed when patients access their own notes. There was some evidence in some settings that patients accessing their own notes might affect the content of nursing notes, or that the way nurses record things in the patient notes may have to change considering the implications of this access. This is not necessarily a bad thing!

Vigilance is needed to maintain a focus on the principles of privacy surrounding electronic patient records, and the purposes of sharing notes (including an explicit conversation with the NZ public about the use and shared access to e-records)

# **Health IT more generally**

Less satisfactory though was the emergence of a picture of somewhat piecemeal implementation, of new developments across multiple platforms, instances where the nursing voice had not informed the practicalities of accessing and making best use of electronic records meaning that the vision of a fully integrated national health record that facilitates clinical coordination and patient care has yet to be realised. Those charged with top level leadership of the national health IT programme may have consulted widely, and no doubt have a clear and appropriate vision: however, there are several key, practical issues from a nursing perspective that will delay and detract from the project if they are not addressed. It should also be remembered that nurses form by far the largest professional grouping in the health workforce. Until easy to use, reliable, and fully functional tools and software are provided for staff, and until the clinical benefits to patients and the administrative and clinical benefits for nurses are apparent (or no alternatives allowed!), there will not be good adherence to and use of new platforms, and the inefficiencies and potentials for lost or inaccessible multiple sets of patient notes will continue.

To some extent, the opportunity for centralised direction and compulsion to purchase and use fully compatible systems has passed. General practices, pharmacies and aged care providers are all private businesses; some of whom have invested considerable time and money on hardware, staff training and systems that currently meet their business objectives. They will have to be compelled, and compensated, if they are to change to a new system – or IT compatibility solutions devised to enable compatibility. From presentations given at the Health Information NZ 2015 conference it was clear this issue has been identified and is being worked on; but for those at the front line who are grappling with less-than ideal systems, multiple launches of different systems and processes will undermine confidence in the ability of the project to ultimately deliver the goals of the project.

# Recommendations

# **Key themes for nurse managers**

> Support and training for nurses using new technologies is key to effective implementation.

# Key themes for policy makers and health IT implementation teams

- > End users not just leaders of these systems need to be involved at all stages of development.
- > There is an urgent need for the development of a mechanism allowing secure access to systems and components that do not require multiple, differently configured and regularly changing computer log-ins. Such systems are available for internet banking, and for Ministry of Social Development (CYF) records by staff all over the country; card readers or centrally programmed electronic random number generators for example could be considered. Without these, the potential for use of the system is diminished.
- Ongoing access to training (until staff are fully competent and confident) on new systems, and IT support through teething problems will be essential for full utility.

# **Key themes for public policy**

- > Communication and dialogue with patients and the New Zealand public also needs to keep step with the changes in electronic shared records, and the purpose, limits and consequences of record holding and sharing.
- If a digital divide is not to increasingly disadvantage poorer or less technologically able or connected health consumers, their inability to access health portals and health information has to be addressed.

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# **Appendix 1. Draft Dissemination strategy**

Audience	Mechanism	Date	Venue
Nurse managers	NENZ Meeting	August 4th	Wellington
Nurse Educators	NNO meeting	August 19 <sup>th</sup>	Wellington
NZNO members	Kai Tiaki – News item	September issue	Journal
NZNO members	NZNO AGM research	September 6th	Wellington
International health IT	Journal Telehealth and Telecare	November, special edition	Journal
Health IT Nurses	HiNZ	November	Auckland
Health IT workforce	HiNZ	November	Auckland
Office of the Privacy Commissioner	Seminar	December	Auckland
NZNO members	Medico-legal forums	3-4 during 2017 Dates TBC	Usually Auckland, Wellington, Christchurch and another
NZNO members	Website – project report.	See example in Appendix 7	On sign off from the OPC

# **Appendix 2. Draft Position Statement**

# Nursing, technology and health IT Position Statement

# **Purpose**

The purpose of this statement is to highlight the professional nursing issues raised by the rapidly evolving advances in electronic health records, health IT and the use of technology in nursing practice.

# **Background**

Advances in the fields of informatics, communication and technology (ICT) have huge potential to improve integration and access to healthcare for all – including patients in remote areas of New Zealand where consultations with specialists can involve considerable travel, cost and inconvenience. New technology also allow timely and accurate communication with patients, facilitating care. Developments in electronic health records pave the way to greater sharing and coordination of care, and encrypted, protected sharing of results, scans, assessments and care plans that will improve patient care and make best use of scarce clinical resources.

Nurses, especially nurses working in the community, have a key role to play in realising these benefits.

# **Definitions**

Health IT is defined as "Health care delivery, or closely related processes, when participants are separated by distance, and information and communications technologies and infrastructures are used to overcome that distance" <sup>1</sup>

The functional domains covered include telephone triage, interactive disease management monitoring (for example sharing of wound care progress via digital images or oversight of devices capable of transmitting data such as blood sugar), and delivery of health information and education.<sup>2</sup>

This briefing statement does **not** address the regulatory concerns relating to clinicians based outside New Zealand being involved in the assessment, diagnosis, and treatment or monitoring of New Zealand patients, though we advocate for appropriate oversight and consideration of this increasingly prevalent practise. Current examples include outsourcing of specialist triage

health lines to Australian paediatric nurses and the assessment and reporting by overseas consultants of biochemical, cellular or radiological investigations.

The Nurse Executives of New Zealand has developed a position statement on health IT<sup>3</sup>. This statement helpfully outlines the key considerations relating to the use of health IT by nursing, and also provides advice to nurses on how to manage those. The NZNO endorses the useful and practical guidance it provides

Additional practical guidance on those topics that may be of a particular concern to nurses, includes advice that:

- > The care nurses provide to a patient in another location should, so far as is possible, meet the same standards as care provided in-person.
- Nurses are responsible for the evaluation of information used to inform their decision-making.
- If technology is unable to provide the information necessary for the provision of appropriate nursing care, then the nurse should either obtain that information by another means (for example, by arranging a physical examination) – or make alternate arrangements for care (for example, by referring the patient to another provider).
- Institutions which implement health IT nursing services should have in place:
  - o policy and procedure including appropriate role/job descriptions
  - regular training, performance monitoring, competency assessment, and quality improvement activities
  - written protocols or guidelines to guide health IT nursing practice, which are regularly reviewed and revised by appropriate stakeholders.

Given the particular legal issues associated with prescribing, additional guidance for nurse prescribers and nurse practitioners may be found in the Medical Council's *Statement on health IT*<sup>4</sup>.

# Strategy

An E-Nursing strategy is required to integrate the physical/practical, educational and regulatory changes that will be required to realise the

potential benefits of health IT and technology outlined in the 2016 Health Strategy. In particular, the nursing profession must continue to engage at all levels with those charged with designing and implementing health informatics in New Zealand (National Health IT Board), and NHITB must ensure that what is developed meets the *clinical* needs of health and nursing workforces, not vice versa.

#### To meet this aim:

- NZNO advocates for secure, shared electronic patient records capable of representing the clinical practice of registered nurses across all fields and settings, designed to enable the recording of clinical data that will facilitate safe coordination of care and robustly capture nursing practice and patient outcomes.
- NZNO asserts that funders and planners must deliver the appropriate investment in technology, training, ongoing ICT support and change management required in the short term to realise the service improvements and reorganisations that may enable cost containment in the longer term.
- NZNO will work with nursing regulatory and professional bodies to provide leadership and support to ensure nurse education to enable safe use of new technologies and development of guidelines to ensure that nursing interventions continue to be informed by nursing values, albeit within changing methods and models of care.
- NZNO will regularly review national and international guidelines and professional nursing advice to keep pace with developments in the fields of ICT and Health IT.

#### Resources

- 1. The NZ Health IT Forum "what is health IT".
- NH Board of Nursing Position Statement and Clinical Practice Advisories
   Regarding the Role of the RN and LPN in Health IT Nursing

- 3. Nurse Executives of New Zealand (2015) position statement on Health IT
- 4. The Medical Council's Statement on health IT (2016)

# **Acknowledgement**

The authors wish to acknowledge the Office of the Privacy Commissioner, New Zealand for supporting this project.

Date adopted: XXXXX2016Reviewed: Month Year, Month YearReview date: August 2021Correspondence to: nurses@nzno.org.nz

Principal author: Dr Léonie Walker, Principal Researcher, NZNO.

#### Mission statement

NZNO is committed to the representation of members and the promotion of nursing and midwifery. NZNO embraces te Tiriti o Waitangi and works to improve the health status of all peoples of Aotearoa/ New Zealand through participation in health and social policy development.

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# Appendix 3. Draft Guideline

# Privacy, Confidentiality and Consent in the Use of Exemplars of Practice, Case Studies, and Journaling

# **Purpose**

The purpose of this document is to provide guidance to nurses, midwives, students and others who may use exemplars, case studies or journaling as part of their practice (including use for professional development and recognition programmes).

# Introduction

The use of exemplars of practice, case studies and journaling of practice experience has become common place within nursing and midwifery over the last 20 years. These three strategies for aiding reflection on practice and demonstrating competence are useful in analysis of strengths and weaknesses and identifying growth or change potential; they are professional development and quality improvement strategies.

Exemplars, case studies and journals are used for multiple purposes including:

- > education programme requirements;
- > professional learning and development;
- > professional development and recognition programmes (PDRP);
- > credentialing systems;
- > recognition of prior learning;
- > competence assessment;
- > describing and exploring clinical practice;
- > evidence of a level of practice development;
- > presentations in various contexts;
- > publications.

The use of exemplars for these legitimate reasons is not without risk. This guideline will provide information on how to manage privacy, confidentiality and consent in order to ensure the safety of the patient and clinician.

# The Legislative and Regulatory Framework

The Code of Health and Disability Services Consumers' Rights ("the Code") issued under the Health and Disability Commissioner Act 1994, the Health Information Privacy Code ("HIPC") issued under the Privacy Act 1993, the Code of Conduct for Nurses (Nursing Council of New Zealand, 2012), and the Code of Conduct for Midwives (Midwifery Council of New Zealand, 2010) are important documents to guide nurses in their use of exemplars, case studies and journals.

# Nursing Council and Midwifery Council Codes of Conduct

The Nursing Council of New Zealand's Code of Conduct (2012) outlines eight principles that nurses should adhere to in their professional practice. The one relevant to this discussion is Principle 5: respect health consumers' privacy and confidentiality.

The sections of Principle 5 are as follows:

- 5.1 Protect the privacy of health consumers' personal information.
- 5.2 Treat as confidential information gained in the course of the nurse-health consumer relationship and use it for professional purposes only.
- 5.3 Use your professional judgment so that concerns about privacy do not compromise the information you give to health consumers or their involvement in care planning.
- 5.4 Inform health consumers that it will be necessary to disclose information to others in the health care team.
- 5.5 Gain consent from the health consumer to disclose information. In the absence of consent a judgement about risk to the health consumer or public safety considerations must be made.
- 5.6 Health records are stored securely and only accessed or removed for the purpose of providing care.
- 5.7 Health consumers' personal or health information is accessed and disclosed only as necessary for providing care.
- 5.8 Maintain health consumers' confidentiality and privacy by not discussing health consumers, or practice issues in public places including social media. Even when no names are used a health consumer could be identified.

The Midwifery Code of Conduct section 1.1 states: that personal information is obtained and used in a professional way that ensures privacy and confidentiality for clients.

In order to uphold the principles of their respective codes of conduct, nurses, midwives and students of nursing or midwifery must ensure that patient confidentiality and privacy are not breached at any time while writing an exemplar,

case study or journal. Neither must they access patient notes to assist in writing an exemplar, case study or journal without consent of the patient (or the patient's family if the patient is unable to give consent), and of their manager. Consent may be written or verbal but if it is verbal this should be documented and ideally signed by the patient or patient's family. Appendix one has a template for consent.

# The Code of Health and Disability Services Consumers' Rights

The Code of Health and Disability Services Consumers' Rights (1996), or "The Code of Rights" or "the Code", as it is known, sets out the 10 rights consumers can expect from their health or disability service providers. Providers and individual health practitioners are obliged to uphold the 10 rights by law. Further information on the Code can be found in the NZNO document of the same name or on the Health and Disability Commission website: www.hdc.org.nz.

Most of the ten rights apply to the use of exemplars and case studies. Specific rights to be aware of include:

Right 1 – Right to be treated with respect.

Right 2 – Right to freedom from discrimination, coercion, harassment, and exploitation.

Right 5 – Right to effective communication.

Right 6 – Right to be fully informed.

Right 7 – Right to make an informed choice and give informed consent.

Right 9 – Rights in respect of teaching or research.

Right 10 – Right to complain.

In summary, if writing exemplars or case studies, the patient involved must be fully informed, give informed consent and be made aware of what the exemplar or case study will be used for. The patient has the right to complain about any exemplar or case study and the exemplar or case study must be written in a manner that respects the patient.

# **Health Information Privacy Code**

The Health Information Privacy Code 1994 (HIPC) provides guidance around the collection, storage, access and use of health information whether stored electronically or in paper form. The code outlines a set of 12 rules health agencies and their agents must adhere to. The rules are as follows:

- > Rule 1 Purpose of the collection of health information
- > Rule 2 Source of health information

- > Rule 3 Collection of health information from the individual
- > Rule 4 Manner of collection of health information
- > Rule 5 Storage and security of health information
- > Rule 6 Access to personal health information
- > Rule 7 Correction of health information
- > Rule 8 Accuracy etc of health information to be checked before use
- > Rule 9 Retention of health information
- > Rule 10 -Limits on use of health information
- > Rule 11 Limits on disclosure of health information
- > Rule12 Unique identifiers.

The HIPC can be found here: https://www.privacy.org.nz/assets/Files/Codes-of-Practice-materials/Consolidated-HIPC-current-15-Oct-2015-inc-amdmts-2-8.pdf

Of particular relevance to writing exemplars, case studies or journaling, is rule 11 and the limits on disclosure of health information. Rule 11 (1) (b) states:

A health agency that holds information must not disclose the information unless the agency believes, on reasonable grounds that the disclosure is authorised by:

- (i) The individual concerned; or
- (ii) The individual's representative where the individual is dead or is unable to give his or her authority under this rule.

#### However, Rule 11 (2)(c) states that:

Compliance with paragraph (1)(b) is not necessary if the health agency believes on reasonable grounds that it is either not desirable or not practicable to obtain authorisation from the individual concerned and that: (c) the information:

- i) is to be used in a form in which the individual concerned is not identified; or
- ii) is to be used for statistical purposes and will not be published in a form that could reasonably be expected to identify the individual concerned; or
- iii) is to be used for research purposes (for which approval by an ethics committee, if required, has been given) and will not be published in a form that could reasonably be expected to identify the individual concerned."

If information from patient records, regardless of whether these are electronic or handwritten, is to be used for writing case studies, exemplars or journals, and Rule 11(1)(c) (i), (ii) or (iii) applies, then the health practitioner may not need to seek consent of the patient. However, access to patient records for the purposes of writing exemplars, case studies or journals must adhere to the Code of Health and Disability Services Consumers' Rights, the Health Information Privacy Code and the Nursing and Midwifery Councils of New Zealand Codes of Conduct. In order to adhere to the requirements of all four codes, NZNO recommends seeking informed consent from the patient or their authorised representative in all situations. Where informed consent cannot be obtained, the health practitioner should avoid using the situation.

# **Disclosure**

Health practitioners have both a legal and ethical obligation to uphold confidentiality. Health practitioners are often in a position where they hold information that should be kept confidential. Writing a journal, exemplar or case study is no different and the obligation to maintain confidentiality must be upheld. Breaches of confidentiality can result in professional disciplinary action being taking against the practitioner or legal action being taken against the practitioner by the patient or the patient's family in a civil law suit, or as a result of an investigation. The following case study outlines the implications for nurses if they access patient records inappropriately.

# Case study – Inappropriate access for PDRP

In 2014, a registered nurse was charged by a Professional Conduct Committee (PCC) of the Nursing Council of New Zealand (NCNZ) with misconduct under the Health Practitioners Competence Assurance Act 2003 (the HPCA Act). The Charge related to inappropriate access or viewing of electronic records of patients or colleagues on an electronic reporting system when the nurse knew or ought to have known they had no authority to do so. The charge referred to 22 different persons and 66 different dates of access to records, in many cases on more than one occasion. The nurse claimed six of the different people for whom records were accessed were persons whose records the nurse accessed as part of a nursing follow-up or for a Professional Development and Recognition Programme (PDRP). The Health Practitioner Disciplinary Tribunal hearing the charge did not accept the evidence given by the nurse, particularly as to the reasons behind access to records. The Tribunal ordered: that the nurse be censured; that after the nurse recommences practice, for a period of three years they practise on condition that they satisfy the NCNZ that they have already undertaken, or will, a course of training and education on questions of patient privacy and confidentiality and the appropriate statutory, regulatory and ethics provisions of the Privacy Act 1993 and the Health Information Privacy Code 1994; and that the nurse contribute the sum of \$26,400.00 towards the costs of the PCC and the Tribunal in respect of the Charge.

Full details of the case can be found here: http://www.hpdt.org.nz/portals/0/nur14302pdecisionweb.pdf

# Risk

In some situations, a practitioner or student may disclose incompetent, unethical or unsafe practice in the course of writing an exemplar. Any disclosure has the potential to influence the reader (whether manager, mentor, preceptor, lecturer or tutor) positively or negatively and there is a risk that students will fail assessments or practitioners may be over looked for promotion as a result of disclosure. While

students and practitioners are encouraged to be honest in their reflective accounts, they should also be aware of the risks.

Although rare, journals, diaries, case studies and exemplars of health practitioners can be requested as evidence in investigations or court proceedings. If the reflection said such things as 'In hindsight I think I should have done "x", or I would not do "y" in the future', this may be taken into account if the practice of the practitioner is under investigation. If a practitioner is asked to write a reflection or exemplar as part of an investigation, then NZNO strongly recommend you contact the NZNO Member Support Centre prior to writing.

There is some protection for the nurse within the Health Practitioners Competence Assurance Act 2003. The Minister of Health can approve quality assurance activities, and participation in such approved activities has wide protection from disclosure in other forums (such as professional misconduct hearings). Thus comments regarding ones own or a colleague's poor practice will generally not be able to be disclosed. This protection extends to documents created solely for the purposes of the quality assurance activity. Note however there are limited exceptions to the non-disclosure rule here, such as where there is evidence of a serious criminal offence.

# Guidelines for the Use of Exemplars, Case Studies and Journals (including within PDRP and student assignments)

Privacy, confidentiality and consent are essential in the use of exemplars, case studies and journaling. Exemplars and journals (and to some extent case studies) use narratives about nurses, colleagues, patients, relationships, care and context. It is very easy to breach privacy and confidentiality inadvertently even if pseudonyms are used. Even a description of an entire context of a situation can result in those involved being identifiable. New Zealand is a small country and contextual descriptions along with the author's location can result in identification of those involved in the exemplar. Nurses and midwives care for the whole person and their family in particular practice contexts and locations; that is what makes our practice complex and significant but it is also these details which often build an identifying picture.

NZNO makes the following recommendations:

Nurses, midwives and students of nursing or midwifery need to comply with the HIPC, the Code of Health and Disability Services Consumers' Rights, and their ethical obligation of confidentiality as per Principle 5 of the Nursing Council of New Zealand's Code of Conduct and Section 1.1 of the Midwifery Council of New Zealand's Code of Conduct when they are writing exemplars, case studies or journals.

- > Recommended best practice for nurses, midwives, educators and students of nursing or midwifery is to talk with patients about what is involved in reflective practice and seek written or verbal consent from the patient, the patient's family, or the patient's legally appointed guardian if the patient is unable to give consent, prior to writing an exemplar or case study. A copy of the consent form should be kept in the patient's notes. A template for written and verbal consent is found in Appendix One.
- Discretion should be used when seeking consent. If a patient or patient's family expresses or demonstrates any concern or duress during the consent process, then it is recommended the consent process is stopped altogether or delayed until a more appropriate time can be found. Students may wish to be accompanied by their educator or other staff member while seeking consent.
- > Unless the patient has consented to identifiable material about them being disclosed then no information that could identify the patient should be put in an exemplar or case study;
- > In order to protect the privacy of patients and practitioners, information that may identify them should be removed or changed. Such information may include name, geographical location, occupation, job title, and/or context. It is important the practitioner or student review the exemplar, case study or journal note with a critical eye, taking into consideration all contextual factors that may identify the client. When making such changes, the health practitioner may draw on information from patients with similar problems to make the changes relevant to the experiences of the patient group as a whole.
- > A statement describing any changes have been made should accompany the exemplar or case study.
- > Patient notes should only be accessed to support writing the exemplar or case study with consent from the patient (or patient's family or legally appointed guardian if the patient is unable to give consent) and the practitioner's manager, and only if the patient is, or has been, cared for by the nurse, midwife or student.
- > Written consent should be obtained where possible. Where this is not possible, verbal consent should be documented with the date, time and any witnesses.
- > It is never acceptable to download or print off patient notes for the purposes of learning.
- > Rule 11 (2)(c) (iii) of the HIPC may be enacted if the exemplar or case study is being written for the purposes of research and ethical approval has been given. However, NZNO recommend that consent of the patient (or patient's family or legally appointed guardian if the patient is unable to give consent) is sought in all cases.
- > Where informed consent cannot be obtained, the health practitioner should avoid using the situation.
- > If an exemplar is solely for private reflective practice and will not, in theory, be disclosed to anyone else, we still recommend the same processes outlined above are followed. Journals may be inadvertently left where others can read them resulting in a breach of privacy.
- > It is never acceptable to put excerpts from exemplars, case studies or journals on Facebook regardless of privacy settings.

- > The nurse, midwife or student should be aware that if a formal investigation involving the nurse, midwife or their patient(s) occurs, then any private journal or exemplar may be required as evidence.
- Organisations should review their policies and procedures around access to patient notes for the purposes of professional development and ensure a robust structure that outlines the required consents and procedures for access is in place. Part of this review could be consideration of a blanket patient request and consent process for the use of anonymised notes for teaching and learning processes.

Despite the potential risks associated with writing exemplars, case studies or journals, NZNO recommends nurses, midwives and students of nursing and midwifery continue to use the writing process as a tool for reflection and learning. Our guidelines identify a number of risks but also a number of approaches for managing these risks. NZNO hopes practitioners will use the guidelines to develop safe practice in the writing of exemplars, case studies and journals.

Further information and examples of reflective writing can be found in NZNO's guideline on Reflective Writing (Clendon, Cook, Blair, Kelly, 2015).

# Acknowledgement

The authors wish to acknowledge the Office of the Privacy Commission for supporting this project.

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Date adopted: Month YearReviewed: Month Year, Month YearReview date: Month YearCorrespondence to: nurses@nzno.org.nz

Principal author: Jill Clendon, Nursing policy adviser/researcher

#### **Mission statement**

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## **Appendix 1. Template for consent**

Page 1.

#### [YOUR INSTITUTIONAL LETTER HEAD]

Informed Consent Form for patients/clients/consumers who are invited to give their consent for a health practitioner or student to access their notes, and/or use any information gained in the course of providing care to the patient/client/consumer, for the purposes of writing an exemplar, case study or reflection.

[Name of nurse/midwife/student/health practitioner] [Name of Organization/University/Institute]

#### **Purpose**

One of the most important learning tools for nurses, midwives and students of nursing or midwifery is to reflect on practice. Often this takes the form of writing an exemplar, case study or journal. In order to gain the most from this practice, it is sometimes helpful to review patient or client notes. This form is to seek your permission to review your notes, and/or use any information gained in the course of providing care to you, for the purposes of writing an exemplar, case study or journal note. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me, my clinical teacher or the unit manager.

# What reviewing your notes, and/or using information gained in the course of caring for you, will involve

Reviewing your notes will involve me accessing and reviewing these at the nurse's desk. I may need to review the notes several times to obtain all the information I need but I will never remove your notes from this area. Any information you have shared while I have been providing care to you may also help inform an exemplar, case study or journal note.

#### **Voluntary Participation**

Giving your consent for me to review your notes and/or use your information is entirely voluntary. You do not have to say yes. Whether you choose to say yes or no, all the services you receive will continue and nothing will change.

#### Anonymity

Information obtained from your notes, and/or in discussions with you, and used in any exemplar, case study or journal will be completely anonymized. This means anyone who is reading the exemplar, case study or journal note will not know that it is you. Any details that may identify you will be changed – this includes your name and any specific details that may identify you such as where you are from.

#### Sharing the exemplar, case study or journal note

Once any details that may identify you have been removed, the exemplar, case study or journal note may be shared with others including (but not limited to) my teachers, other colleagues and/or other students. In some cases, the exemplar or case study may be published in an academic or industry journal in order to help others learn. You will be given or shown a copy of the exemplar, case study or journal note if you wish.

#### Right to Refuse or Withdraw

If, after reading the exemplar, case study or journal note you would prefer for it not to be shared, you have the right to say no to this.

#### Who to Contact

If you have any questions, please contact me [name] on [phone number], my teacher [name] on [phone number] or the unit manager [name] on [phone number].

Page 2

#### **Part II: Certificate of Consent**

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to:

		Yes	No			
	1. Allowing [name of person seeking consent] to access my notes for the purposes of writing an exemplar, case study or journal note.					
-	2. Allowing [name of person seeking consent] to use any information gained in the course of providing care to me for the purposes of writing an exemplar, case study or journal note.					
_	3. Allowing [name of person seeking consent] to share an anonymized exemplar, case study or journal note with their teacher/colleagues/students for the purposes of learning.					
-	4. Allowing publication of the anonymized exemplar, case study or journal note in an academic or industry journal.  5. I would like to read or have read to me the anonymized exemplar, case study or journal note.					
-						
Any other comments or notes:						
Print	Name of Patient					
Signa	ture of Patient					
Date _	Time Day/month/year					

#### Witness in the case of verbal consent:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness		Signature of witness	
Position of Witness			
Date	Time		

### **Appendix 4. Abstracts**

Abstracts accepted for the HiNZ Conference, Auckland, November 2016

Abstract One: The case for end user involvement in design of health technologies.

#### Aim

To explore the views, expectations, practice and attitudes of registered nurses and nurse leaders working in community/primary health care settings concerning the use of mobile devices and data storage platforms.

#### Method

A mixed methods approach including an environmental scan and individual, paired and focus group interviews with 36 nurses working in the community and nurse leaders/managers. Data were analysed using a general inductive approach (Thomas, 2006). Ethics approval was gained from the Victoria University of Wellington Human Ethics Committee.

#### Results

Nurses have excellent understanding of issues associated with privacy, consent and the use of health IT. With targeted, individualised education nurses use health IT effectively. Significant barriers to/concerns associated with the use of health IT include: having to concurrently complete paper and electronic patient notes; multiple logins for multiple systems resulting in forgotten passwords, sharing of passwords and/or inadequate use of essential systems; lack of infrastructure in some settings – particularly those that are privately owned; inadequate systems for the use of digital cameras (e.g. for tracking wound healing); and the inability to access patient notes across systems to ensure integrated care.

Ways in which barriers can be addressed include designing systems from the ground up in collaboration with nurses who will use the system, providing individualised education and ongoing support, single swipe card log on systems, increased funding for private sector providers, and improved interface for mobile technology such as digital cameras and clinical applications for smart phones.

#### Conclusion

Nurses are the largest group of health practitioners in New Zealand and are at the front line of patient care. Nurses need a good understanding of health IT in order to be able to use it effectively and facilitate patient use and understanding. Further work is required to ensure nurses are fully engaged with the potential of health IT and its use.

#### Reference:

Thomas D. (2006) A General Inductive Approach for Qualitative Data Analysis. University of Auckland, Auckland, New Zealand.

Abstract Two: Patient privacy and electronic health records: views of nurses working in the community.

#### Introduction

Nurses in community settings are increasingly using digital devices to access patient notes in the home and/or complete electronic records of their visits. They also increasingly have access to multiagency records to enhance integrated care. Privacy and confidentiality are cornerstones of nursing practice and it is essential nurses have a good understanding of both in the use of e-health records and other emerging technology. However, little is known about the attitudes, views, expectations, and practice of nurses in this regard.

#### Use of technology

This presentation will discuss the findings of case studies undertaken with nurses working in two community/primary health care settings (one rural, one urban) concerning the use of technology and the practical, confidentiality and privacy issues surrounding access to electronic patient records and notes.

#### Implementation/processes

Each site had distinctly different experiences and approaches to the use of ehealth records and other technology. In the rural case study, inter-professional communication was enhanced as people knew one another but privacy became problematic for the same reason. Poor integration of multi- disciplinary records and problems incorporating peripheral technology (e.g. cameras) was described. Although nurses had access to some electronic files, this was patchy. In the urban case study, all notes were handwritten in traditional patient files, and lack of shared electronic records across providers and multidisciplinary teams limited the potential of e-records.

#### Conclusion

While nurses in both case studies had good understanding of privacy and confidentiality, for many reasons, the full potential of e-health is far from being realised. Greater understanding of nursing practice requirements, and of the practicalities of the role is urgently required. Nurses also need individualised education, consistent messages and support to integrate e-health into their practice.

**From:** Tori Wade [mailto:tori.wade@adelaide.edu.au]

**Sent:** Sunday, 17 July 2016 11:25 a.m.

To: Leonie Walker < Leonie W@nzno.org.nz>

Subject: Offer of publication Special Issue JTT for SFT-16

#### Dear Leonie

Following a review of the abstracts submitted to the SFT-16 conference, your work The case for end user involvement in design of health technologies has been selected for possible publication in a special issue of the *Journal of Telemedicine* and *Telecare (JTT)*. The special issue will be comprised of short papers and be published in November 2016, coming off embargo at the first day of the conference. If you are interested in submitting a paper, please let me know by return email as soon as possible, as timelines are tight; if you do not wish to take up this offer we will offer the opportunity to another author.

The Author Guidelines are attached. If you have any additional questions do not hesitate to contact me directly.

best wishes Tori Wade

Dr Victoria (Tori) Wade BSc, DipAppPsych, MPsych, BMBS, PhD, FRACGP Senior Research Fellow, Discipline of General Practice, The University of Adelaide email victoria.wade@adelaide.edu.au web www.e-unicare.com.au

# Appendix 5. Paper submitted to Journal of Telemedicine and Telecare

Title: The case for end user involvement in design of health technologies

Léonie Walker, BSc, MSc, PhD Principal Researcher New Zealand Nurses Organisation, Adjunct Professor, Graduate School of Nursing & Midwifery, Victoria University Wellington

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(agreed correspondent)

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#### **Disclosure Statement:**

Both authors are employed by the New Zealand Nurses Organisation. The project was part funded by a grant from the Office of the Privacy Commissioner, New Zealand.

#### Summary

This paper reports a subset of data from a mixed methods project interviewing nurses working in the community and nurse leaders/managers to explore the views, expectations, practice and attitudes of registered nurses working in the community concerning electronic health records and the use of mobile devices. Nurses displayed excellent understanding of privacy, consent concerning electronic patient records and health information technology (e-health). With targeted, individualised education, nurses use e-health effectively. However, significant barriers were found regarding duplication of paper and electronic patient notes and multiple logins for different platforms and systems resulting in forgotten and shared passwords. There was also evidence of some avoidance of essential systems; lack of infrastructure in some settings; inadequate systems for the use of digital cameras (e.g. tracking wound healing); and inability to access patient notes across settings to ensure integrated care. In conclusion, nurses are the largest group of health practitioners in New Zealand and are at the front line of patient care. Nurses need systems designed around their work methods and a good understanding of e-health in order to be able to use it effectively. Greater consultation with nurses is required to ensure the potential of e-health and its use is maximised.

Key words: E-health, nurses, user-involvement, New Zealand

Full paper will be available on publication.

## **Appendix 6. NENZ Presentation**

Notes pages relating to dissemination at two high level nursing leadership meetings.

- 1. Nurse Executives NZ, Wellington August 4<sup>th</sup>. NENZ represent Directors of Nursing for DHBs, PHOs, the Aged Care Association and Private hospitals.
- 2. NNO (National Nursing Organisations), Wellington, August 19<sup>th</sup>. NNO represent the Office of the Chief Nursing Officer, Heads of School for nurse education and the College of Nurses Aotearoa.

# Health IT and privacy

#### Community nurses:

Knowledge of privacy issues Practicalities of implementation

Project funded by the Office of the Privacy Commissioner.

Aim was to examine Nurses working in the community' Knowledge of privacy issues around use of e-health technology.

There have been many recent developments in health information technology and its increasing use by multidisciplinary teams. These include the development of systems by which patient records and results are stored and accessed in digital formats throughout the health system Personal health information is increasingly available (with appropriate access) across disciplines and health care organisations. Settings can include: patients homes; primary care; secondary care; residential care; and pharmacies. Disciplines include: doctors; nurses; allied health professionals; social workers and pharmacists. Devices such as lap tops, tablets, and smart phones which have functions such as internet access, bluetooth, video and sound recording capacity may now (or shortly will) be taken out and used in the community, and within people's homes. Considerable input has been made at the highest professional levels regarding patient record access, data security and the privacy safeguards required of the new systems. This includes the development of guidelines. However, how this input is understood or acted on by nurses working directly with patients in the community was not known.

Funding was sought and obtained from the Office of the Privacy Commissioner

# Approach

- Document Review
- · Interviews and focus groups with 36 key informants:
  - Nurse Leaders
  - PNA
  - District Nurses
  - Nurse Managers
  - · Medico-legal Lawyers
  - · Rural Practice Nurses

#### Methods

Mixed methods:

Document review (codes of ethics, nursing council, NENZ own excellent guidelines) Interestingly, DHB policies were not available except by intranet log in! Individual, paired and focus group interviews (again many thanks to those of you who were interviewed, provided feedback or facilitated participation of your staff.)

Data were recorded, transcribed and analysed descriptively using a standard inductive approach

# **Findings**

#### Nurses' knowledge of privacy is excellent

- · Key themes for nurse managers
- Key themes for health IT implementation teams
- Key themes for public policy

**Nurses' knowledge of privacy is excellent!** A couple of issues we picked up: Some were unsure of why it was an issue to look at your own medical records, technically when students were on placement some policies and procedures regarding students shadowing logged in nurses? And the use of notes of patients nurses had cared for, for reflective practice was brought up as a complex and confusing issue (see later) Although it was shown to be legitimate and resolved, when nurses were moved from ward to ward, there were sometimes questions raised about accessing of notes from different sites, causing some anxiety.

**Key themes for nurse managers**: Support and training for nurses using new technologies is key to effective implementation. Needs to be user led (starting where learners start and working with them till they are where they need to be), and ongoing. Ongoing access to training (until staff are fully competent and confident) on new systems, and IT support through teething problems are essential for full utility.

#### Key themes for health IT implementation teams

End users – not just leaders – of these systems need to be involved at all stages of development. One issue we identified is an urgent need for the development of a mechanism allowing secure access to systems and components that does not require multiple, differently configured and regularly changing computer log-ins. Such systems are available for internet banking, and for Ministry of Social Development (CYF) records by staff all over the country; card readers or centrally programmed electronic random number generators for example could be considered. Without these, the potential for use of the system is diminished – an example being the nurses who didn't make use of computer aided decision algorithms due to log in issues. Another issue – an example of the tail wagging the dog was where IT services could not / did not facilitate the easy uploading of photos from digital cameras or smart devices – for example to track wound healing – ironically due to privacy concerns. This led to loss of functional capacity.

We'd support national calls for systems to be compatible, have the same user interfaces etc - would increase use and avoid wasteful inefficiency – though note the Southern DHBs are leading the way here.

#### **Key themes for public policy**

Communication and dialogue with patients and the New Zealand public also needs to keep step with the changes in electronic shared records, and the purpose, limits and consequences of record holding and sharing. You'll have noted Increasing ministry dialogue about patient empowerment and digitally enhanced self-care: m-health smart phones and diabetes apps.....If a digital divide is not to increasingly disadvantage poorer or less technologically able or connected health consumers, their inability to access health portals and health information has to be addressed. (Recent excellent article in nursing review?)

### Outputs

- · Report for the Office of the Privacy Commissioner
- · Position statement on Telehealth
- Updated guidelines
- · HiNZ.

Report for the Office of the Privacy Commissioner

Feedback (anonymized) was given to participants and their line managers

Position statement on Telehealth specific for our members was widely consulted on and now developed.

Jill has updated NZNO guidelines (including wide consultation within the sector and nursing education) on privacy and consent in the use of exemplars, case studies and journaling likewise as a result of findings

2 Abstracts have been accepted for HiNZ conference Nov. One has been invited to be produced as a paper in the Journal of Telehealth and Telecare.

# Appendix 7. NZNO website example

NZNO web site: Publications page - http://www.nzno.org.nz/resources/nzno\_publications Sample:

#### Practice (29)

All documents directly related to the broad scope of nursing and midwifery practice. This includes all documents that describe and provide direction on nursing or midwifery practice issues.

Call to Action: Health literacy policy and practice for nurses, 2012

