

Creating an Electronic National Maternal Fetal Medicine Network

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Abstract

Maternal Fetal Medicine (MFM) is a tertiary level sub-specialty of Obstetrics and Gynaecology that deals with high risk pregnancies. Unlike other tertiary services such as liver transplantation, MFM deals with many different diagnoses, and often provides diagnostic advice rather than particular interventions. Because of the distributed nature of the expertise and the need to deal with many parts of the health system a Coordinated Network of expert centres has been proposed. Along with face-to-face meetings an electronic network has been proposed to facilitate this process.

1. Introduction

Maternal Fetal Medicine (MFM) services in New Zealand are based around Auckland, Wellington, Christchurch and Hamilton. However, much of the diagnosis and care takes place in the primary and secondary sector, and each District Health Board (DHB) may have different patterns for referral. Pregnancy is a particularly complex area for informatics support because it is a normal physiological process rather than a disease, lasts for a limited time and has some characteristics of a long term condition and some of an acute episode. Happily, because of the reductions in maternal and perinatal morbidity and mortality in the developed world, data collection across large areas is increasingly important [1]. A recent paper [2] has outlined some of the difficulties associated with data collection in the community and the complex nature of the patient journey and the funding methods. National statistics are also collated by NZHIS [3].

However, MFM service users are even more complex than a standard pregnant woman. They generate data both as mothers and babies which also requires contextualising with regard to previous and future pregnancies and continuing care of the newborn. Thus a national common database although theoretically attractive in some respects, is unlikely to be practical in the medium term. In particular, effective and timely referral and consultation between tertiary, secondary and primary providers as well as the women and their families is essential. At National Women's Health (NWH) new referrals are expected to be seen within 2 working days. Referral numbers vary widely between different indications – for example some complex case such as twin transfusion syndrome may occur only 10-20 times a year, whereas more common conditions may generate 100-200 referrals for each tertiary centre, and there may be even more requests for information and telephone consultations.

Electronic sources of guidelines are not new and have been extensively studied [4]. In the New Zealand context the new Zealand Guidelines Group [5] has been providing guidelines for many years. However, an integrated electronic network in a particular area of practice to support clinical care that it shared between primary secondary and tertiary level is still uncommon, especially across different organisations.

The New Zealand MFM Network (NZMFMN) was set up in order to coordinate care around the country, improve outcomes for mothers and babies, reduce costs – in particular those associated with transfer of mothers to Australia and improve retention of specialists and their skills within New Zealand.

2. Objectives of the electronic network

The electronic network attempts to fulfil a number of information and information management needs for various user groups as shown in Table 1. It should be emphasised that this network is based around information and knowledge sharing rather than data collection although this may become significant later. This system is also not expected to be a general-purpose guideline repository, but to support the development of the network and improvement in care and efficiency rather than provide an independent information source.

In addition the network provides support to Lead Maternity Carers (LMC) who may have questions which they would normally phone the MFM unit about. A FAQ section will allow LMCs quicker access to answers and reduce the workload of the MFM unit staff.

Table 1 - User group information needs

General Public	Health Professional	MFM Specialist
<ul style="list-style-type: none"> • Provide general information about high-risk pregnancy. • Provide up to date information about local services with support for high-risk pregnancy • Provide information about the four MFM units • Provide information about the Fetal therapy unit in Auckland 	<ul style="list-style-type: none"> • Study resources in High-risk pregnancy • Guidelines/ Patient Information Leaflets • Frequently Asked Questions • Referrals information • Specialists Contact • Updates on teaching opportunities • Other help resources • Provide a way which health professionals can contact specialists for second opinion. 	<ul style="list-style-type: none"> • Share cases asynchronously • Learning • Quality improvement through combined audit and peer review

3. Design of the electronic network

3.1. Web site

An 'ideal solution' was proposed from which a working solution was developed. In this 'ideal solution' there was an entry point to the website accessible by all. At this point general information would be provided: What is MFM, who will the woman see and what will happen, what sort of women are seen, and where would she be seen depending on place of domicile. It was also hoped to have information on the four Fetal Medicine Units. This area is represented by the green squares in Figure 1.

A separate area for the health professional with a low level of security was proposed. This would contain more extensive clinically based information such as guidelines. There would also be information leaflets. These are complex cases and it was felt that the information leaflets would be better used if given to a woman by her caregiver with an explanation. This area would also contain information on teaching and training and FAQs. This area is represented by the purple squares in Figure 1.

In the 'ideal solution' it was planned that the MFM specialists of the four Fetal Medicine Units would have access to a high level security area that would allow transfer of patient data. This would allow specialists to collegially support each other in difficult cases by peer review and feedback. Given this part of the proposal involves transferring confidential data across DHBs it was considered the most difficult part of the proposal. This area is represented by the orange squares in Figure 1.

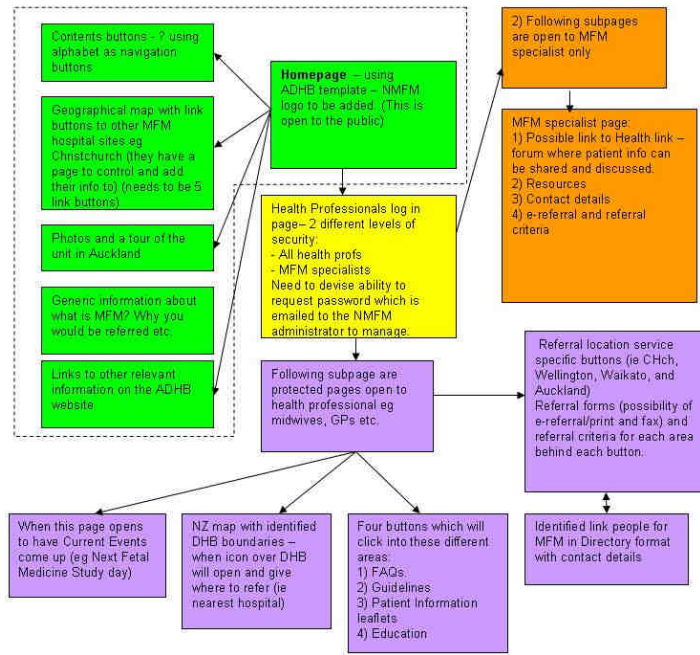


Figure 1 - Planned map of the electronic network

This access plan has recently been modified (see below).

The development process included the authors of the paper, which included a collaboration between NWH staff and a masters student and their supervisor at AUT. This collaboration was helpful in terms of providing some early stage documentation and scoping of the project and also bringing together enthusiasts. As part of the development process a number of use case diagrams were constructed in response to planning meeting. The first (Figure 2) refers to the use of the system by a member of the public with an interest in the area.

Health professionals are involved in more complex use cases (**Error! Reference source not found.**). Following the proposed 'ideal solution' there has been discussion within the project team as to whether there should be multiple levels of health professional access but the current plan gives access to all health professionals who register on the site.

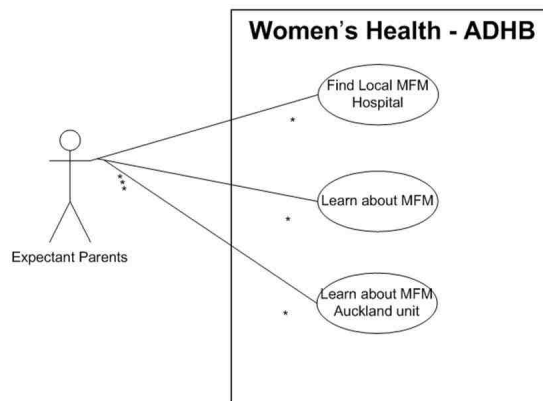


Figure 2 - Use case for expectant parents

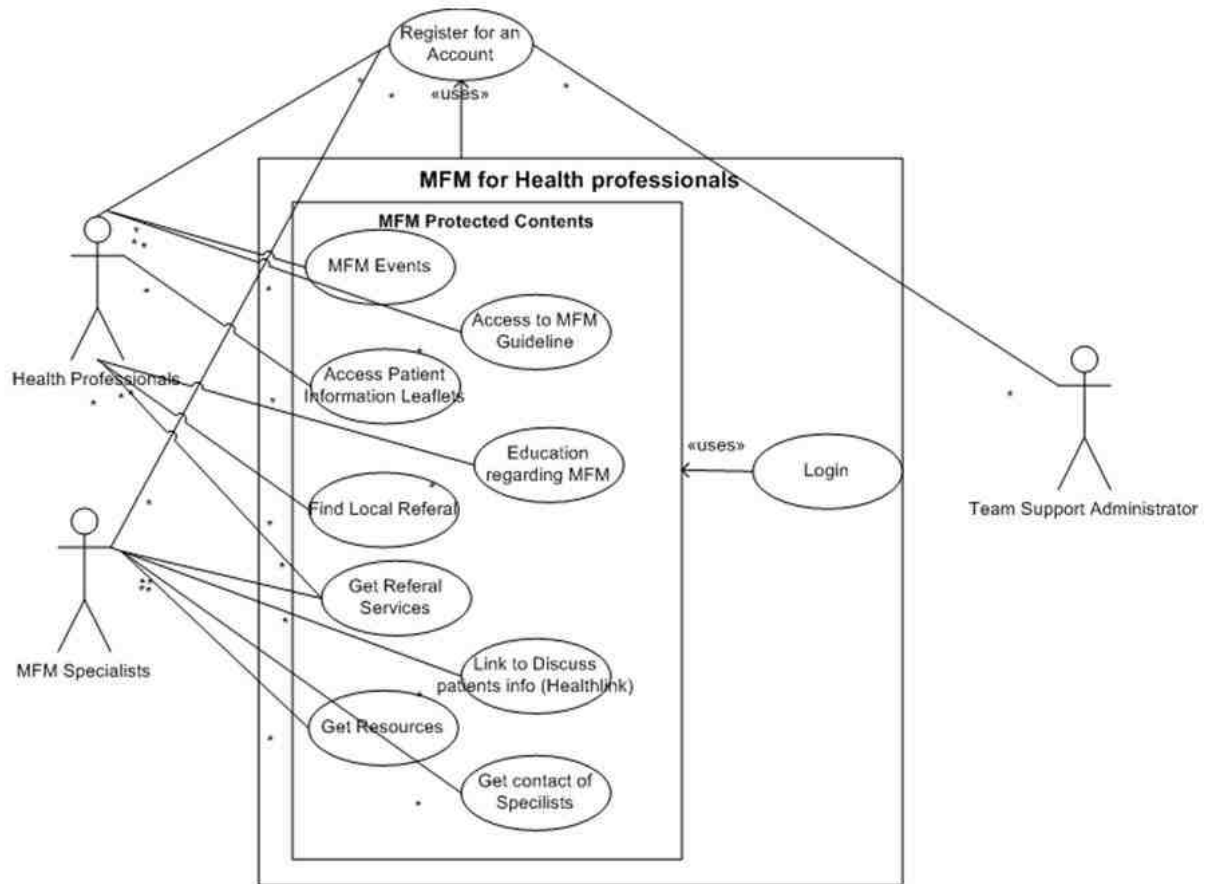


Figure 3 - Use cases for health professionals

4. Current state of the network

Currently the patient information is being populated on Healthpoint and options for development of the various secured and non-secured areas are being explored. Healthpoint is a company employed by a number of DHBs to develop a combined internet based interface to present information to patients and health professionals. The Health professional logs in to gain access to different information of low security importance. Local staff are the keyholders to the information which is entered directly or forwarded to Healthpoint staff to enter. Secondary to the large amount of data and webpages being stored, a broad shallow approach is taken to the website design. Namely, the levels of web pages will go only 2 or three deep at any one place. The corollary of this is that the 'frontpage' has a lot of information on it and needs to be carefully managed via quick links to parts of the page at the top of the page.

A domain has been purchased which the NZMFMN homepage will map to. This will give a unique domain and will provide a clear area to link to from other websites eg RANZCOG, Ministry of Health.

In the new NZMFMN area, there will be a different view for the public and health professionals. When the public access the website there is a homepage with general information. There will be a link to a separate page for each of the four MFM units. These will be 'owned' by the local team who will have administrator rights to their area. There is the potential for links from these pages to the local DHB pages for information required for that particular unit eg parking and visiting hours. Other potential information will include a tour of the unit and what to expect. Some units may place a brief biography and photographs of the team members on the web page.

When a health professional enters the website they will get a different view. On the homepage there will be additional sections on guidelines, patient information leaflets and frequently asked questions. In addition there will be more information on contacts for each unit and where available e-referral facilities. Upcoming teaching and training opportunities will also be listed.

5. Lessons learned

Projects rarely arise in isolation. The New Zealand health environment is rapidly changing as is the electronic environment. Many other clinical networks may be required to efficiently manage the clinical and financial resources of a small country that cannot expect to provide tertiary expertise in each of 21 DHB's. New Zealand Health IT projects are as likely to have problems as ones in other countries [6]. Projects that involve collaboration are often particularly vulnerable.

IT failures are a common occurrence both inside and outside the healthcare sector. A frequently cited article [7] identifies a number of possible causes of failure which include use of immature technology, poor planning and lack of involvement and understanding amongst stakeholders and sponsors. In this project technology does not appear to be a large risk, as the websites are being built via content management systems. This means that the user can generate and publish content without the need to deal with technical detail or bespoke coding. Content management systems generally also have a large user base so informal and vendor support may be available. Stakeholder involvement and support is more problematic, and the role of clinical leaders in this area is vital. Clinical leaders (Fetal Medicine Unit Specialists) are very committed to this project, and are benefiting from early successes. It is planned to keep stakeholders at the forefront as they are likely to be the area of potential risk. Stakeholders include: women and their families, Lead Maternity Carers (LMCs), Obstetricians and Gynaecologists, midwives, sonographers, DHB management and the Ministry of Health. With this diversity of stakeholders, compromises are inevitable, however the essential lesson learned so far is the need to develop an 'ideal solution' which can be readily adapted by the team to the best available resource. It is important that the project team consider all options for their internet presence. Often the proposed 'ideal solution' may be unattainable in its entirety at the current time, with the current vendor or at a cost which is not prohibitive. There may be a combination of these factors. It is better to make a start and build from this.

In addition we are finding that it is important to make the project visible within the organisations and amongst stakeholders as early as possible. This project is an example of an IT solution being partnered with a new Clinical Network to support its development and provide ongoing support.

6. Future work

In the future it is planned to have e-referrals on line via the website. This will streamline referrals and ensure all relevant data included. Within the Auckland Unit this is planned as a DHB wide innovation.

A password protected area with a higher security is planned for the future where the specialists of the NZMFMN units can meet in cyberspace and discuss particular cases online including images. This may follow a similar chatroom style facility provided by the paediatric radiology society.

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8. References

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