Travelling Fellowship Report

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APHCRI STREAM 7
TRAVELLING FELLOWSHIP REPORT

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INTRODUCTION

The aims of this travelling fellowship were:

- To understand how the key findings from the APHCRI Stream 4 Chronic Disease Management review might be interpreted within the context of the UK primary health care system.
- To understand how the process of linkage and exchange between researchers and policy makers operates and is sustained in the UK. What are the components necessary for a sustainable and successful model?
- To understand how this differs from the model used in APHCRI Stream 4 and how the results might be applied to the Australian context.

The Stream 4 project that relates to this travelling fellowship was a systematic review of chronic disease management in primary care [1]. During this review it was apparent that a great deal of relevant research and evaluation was being undertaken around the question of chronic disease management in UK primary care and therefore the National Primary Care Research and Development Centre (NPCRDC) and the Health Service Management Centre (HSMC) were visited as academics from these Centres had led much of this work.

CHRONIC DISEASE MANAGEMENT - THE UK CONTEXT

Health policy makers in Australia and the UK have focused on the increasing role of primary care in the management of people with chronic disease. The approaches taken by the two countries have varied mainly because of the differences in the way primary care is organised and funded. Many of the Australian policy options arising from the key findings of the chronic disease management review focused on support to improve practice level data and payment systems to facilitate greater multidisciplinary team care to support self-management. This is in contrast to the UK where high quality practice level data are used to monitor and reward chronic disease management through the Quality and Outcomes Framework [2]. In addition to this, the payment system for UK primary care favours a multi-disciplinary approach to chronic disease management.

SELF-MANAGEMENT SUPPORT

There is still a need to more firmly embed self-management support in primary care in the UK as there is in Australia. Programmes such as the Expert Patients Programme have been successful at recruiting patients and recent evaluations suggest that it is a useful addition to the services on offer for people with chronic disease [3, 4]. However, the EPP is run by the Primary Care Trust (PCT) and may not involve the GP or have the full support of the GP. In addition to this there has been poor recruitment of people from ethnic minority groups or low socioeconomic class, missing many of those most in need of self-management support [4].

In discussions with PCT Long Term Conditions Commissioning Leads in the West Midlands it was felt that patients were still being given mixed messages and inconsistent advice about the self-management of their condition. One of the PCT members described an ideal patient pathway from diagnosis and then referral to self-management support and multidisciplinary team care with every member of the multidisciplinary team providing consistent information and advice. There is clearly a role for government and non-governmental organisations in working together to ensure consistent information is provided for use by health professionals and patients both in the UK and Australia.

DECISION SUPPORT

Practice level data in the UK have improved since the 1990s and are used extensively in quality improvement for chronic disease management. The Quality and Outcomes Framework utilizes

practice level data to assess GP performance in terms of achieving benchmarks for the management of a variety of chronic conditions. GPs have been successful at achieving the benchmarks and as a result payments to GPs have increased [5]. The programme has been criticised for emphasizing process outcomes and not patient level outcomes [6] and also for promoting a mechanistic "box ticking" approach to patient care. In spite of the criticism of the Quality and Outcomes Framework the experience in the UK highlights how practice level date might be used to support chronic disease management and encourage or reward guideline based care. It would be useful to explore what impact the Quality and Outcomes Framework has had on patient level health outcomes and how to ensure that patients with highly complex conditions or combinations of co-morbidities might be included.

Practice nurses play an important role in the management of chronic disease in the UK. In general they are well trained however a recent survey of practice nurses providing respiratory care found that 20% of nurses providing advanced level asthma care had not undertaken accredited training and this rose to 52% of those providing advanced COPD care [7]. In spite of the increased role of the practice nurse in the UK compared to Australia improving nurse education in the management of chronic disease and self management is still an important policy option for the UK as it is here.

CLINICAL INFORMATION SYSTEMS

In addition to the Quality and Outcomes Framework, data are used to enable practices and PCTs to plan their chronic disease management services at a local level. The PARR (Patient At Risk of Re-hospitalisation) software was developed by the University of York and Health Dialog and is available free for PCTs to download from the Kings Fund website [8]. This program uses hospital and community data to predict which patients are likely to be at risk of readmission so that interventions can be targeted and hospital admission prevented. An example of an intervention to prevent hospital admission is the development of a "virtual ward" where high risk patients are intensively managed in their own home by a multidisciplinary team of health professionals [9].

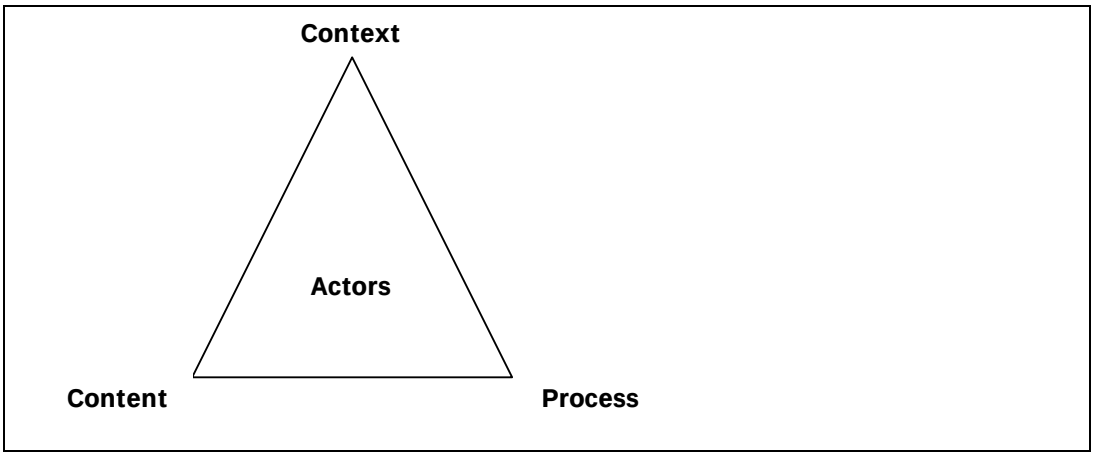
DELIVERY SYSTEM DESIGN

Practice nurses play an important role in the management of chronic disease in the UK and the funding system for UK primary care supports the delegation of some chronic disease management roles from GPs to practice nurses. Multidisciplinary team care approach to chronic disease management has also extended to special health centres that exist as a "halfway house" between primary and secondary care, an example is the Partners in Health Centre in North East Birmingham [10]. The programme has not been evaluated to assess the impact on health outcomes and service use. The model has drawn heavily from the Kaiser Permanente model of care for people with long-term conditions and is linked closely with practice based commissioning. The challenge for both Australia and the UK is to ensure that health professionals are well trained to provide multidisciplinary care and have access to high quality and consistent information. If services are not developed with the support of general practice they may duplicate practice services and may not have the buy-in of the patient's GP.

LINKAGE AND EXCHANGE IN THE UK

"*Research does not influence policy without a strategy. The timing of the research and the policy agendas are important, but even if the research report is timely it may still take a considerable amount of time before the findings of the research influence policy.*" [Martin Marshall, Health Foundation]

As in Australia, the policymaking environment in the UK is increasingly complex and further complicated by an electorate who are well informed and have rising expectations [11]. The framework that is frequently used to think about the highly complex interrelationships is the policy triangle, see Figure 1. This will be used here as a framework for the discussion of the process of linkage and exchange between policy makers and researchers in the UK.



From: Walt and Gilson (1994) [12]

Figure 1 Policy Analysis Triangle

CONTEXT

Between 1997 and 2005 New Labour reformed the UK civil service, one of the aims of the reformed service was to ensure that evidence informed policy decisions. To aid this, the UK Centre for Evidence Based Policy and Practice was formed. It was also decided to open up the civil service to "outsiders" [13]. This strategy included recruiting outside experts into senior posts within the civil service such as "tsars", developing policy units with a mixture of academics and civil servants and appointing non-executive members to departmental managerial boards.

POLITICAL IDEOLOGY

Several of the people interviewed discussed the importance of understanding the political ideology of the party in charge and presenting the findings of research in way that supports or takes into account their ideology. For example:

- Conservative Party ideology is routed in ownership and business type models and resulted in policies such as general practice fund holding in the 1990s.
- New Labour is concerned with tackling health inequalities and equity of access.

It is important to also consider the fact that not all issues can be tackled at once and therefore there are competing priorities and often policy makers will chose the "easy wins" first.

REORGANISATION

A feature of policy making in both Australia and the UK is the frequent turnover of staff. Cabinet reshuffles occur frequently (~every 2 years) and senior policy makers move departments. The impact of this personnel movement is a reduction in "institutional memory", knowledge about previous policies and their impact, within policy departments. When there is a change of government there may be very little handover of information from the previous incumbent. In response to this reduction in institutional memory policy makers are increasingly relying on academic units (such as NPCRDC and HSMC) and independent organisations (such as the King's Fund) to provide this institutional memory. APHCRI is well positioned to be a repository of institutional memory for primary care in Australia with the various spokes providing access to specific "memory" such as rural and indigenous health issues. It has potential advantages over the UK system in that the interaction with policy makers is through one centre and not several and the hub then provides access to further spokes. However, there are potential disadvantages to this model, which will become clear when discussing the relationships between the actors.

ACTORS

There is considerable overlap between the types of actors in Australia and the UK with the notable exceptions of the Tsars. Below are some of the actors involved in UK policy.

Ministers

Special advisers – personal appointees of the Secretary of State

Board of Department of Health – whose role is to focus on high-level health strategy.

Non board members –senior professionals who support and advise the Board

National Clinical Directors (Czars or Tsars) –first appointed in 1999 and this was the first time that clinicians were directly involved in briefing health ministers [14] although senior professionals had been employed in this type of role in other departments such as defence. They tend to be given a fixed contract, commonly 4 years, and then move on, this is to try to ensure innovative thinking, which may become stale with time [13]. They advise the Board.

Chief Professional Officers – senior representatives from the various health professionals.

Senior civil servants – traditionally civil servants were recruited as graduates and to be career civil servants.

Academics – there are a number of academic departments that are involved specifically in health policy with close links to key policymakers. For example: National Primary Care Research and Development Centre (University of Manchester), Health Services Management Centre (University of Birmingham), Health Services Research Unit (London School of Hygiene and Tropical Medicine).

NGOs – there are a number of independent charitable organisations involved in health policy such as the King's Fund.

Consumers / patients- may influence policy through patient support groups for particular conditions lobbying government for change.

RELATIONSHIPS BETWEEN THE ACTORS

A systematic review of the use of research evidence by policy makers published in 2002 identified that the key facilitators and barriers to uptake of research were personal contact between researchers and policy makers and the timeliness and relevance of the research [15]. The relationship between the actors is fundamental to the process of linkage and exchange and this was very apparent in all discussions in the UK. Interaction between policy makers and academics occurred both formally and informally. For example, it was estimated that someone from the NPCRDC would meet with a policy maker on average every three weeks and considerable time and effort was invested developing relationships with people in key policy and communications departments. Academic staff have been sent on communication and networking courses to develop their skills in this area in order to maximise opportunities. The importance of face-to-face contact was stressed by all academics and policy makers interviewed. The nature of relationships between researchers and policy makers was likened to the concept of continuity of care in general practice. It was regarded as being important to maintain and manage the relationship and continuity of information [16]. By facilitating this as a continuous relationship it enables the development of mutual trust.

Developing and maintaining relationships is an ongoing process, especially with the frequent changeover of key actors. The Health Service Management Centre has strong relationships with policy makers and senior health service managers as many may have been on the NHS Management Training Scheme, which is run by the Centre. This helps to maintain contact with key managers and policy makers even after reorganisation.

Chris Ham has had experience as both an academic and a senior policy advisor. His experience in policy was useful in highlighting how policy makers work and that it is not always the lead policy maker that you need to have a relationship with. He felt that over the years it has become easier to make direct contact with policy makers. Where possible and feasible he

would aim for direct contact such as a telephone call or face-to-face visit. This highlights once again the importance of the one to one relationships in cultivating effective linkage and exchange as described by Jonathan Lomas at the Canadian Health Services Research Foundation [17].

The experience during the APHCRI review highlighted the difficulties in developing and maintaining a relationship with relevant policy makers at a Commonwealth or State level. The relationships were brokered through the APHCRI hub, which arranged for key policy makers to attend workshops. Given the importance of face-to-face contact it might have been beneficial for members of the research team to meet with relevant policy makers in person at least once during the project. The communication between our spoke and policy makers was by telephone and e-mail as the key contacts for our project were not present at the workshops. Without the justification of the project the relationships with policy makers developed during APHCRI 4 have not been maintained. There may be capacity issues here in that if all spokes maintained their relationships with policy makers then policy makers are likely to become overwhelmed. The APHCRI hub is in a position to maintain and develop these relationships without overwhelming policy departments but this is at the expense of the one to one relationship development with the spokes. Geographically it is potentially more complex to maximise opportunities for relationship building in Australia compared to the UK. Academics based in capital cities are within easy reach of state health departments but may be some considerable distance from Canberra.

TIMING OF INTERACTION

Both the National Primary Care Research and Development Centre and the Health Service Management Centre have systems in place to ensure the timeliness of their research. The key feature is up to date literature on the key research streams of the Centre. The Director of Communications at the NPCRDC produces a weekly internal newsletter that contains:

- All NPCRDC publications for that week
- Citations of NPCRDC publications for that week
- Policy information relating the streams of work from a variety of sources including government press releases, mass media, journals
- Any other publications relevant to streams of work
- Information about how the research of the Centre has been used (citations, policy bulletins or briefs, citations in the media)
- Presentation of Centre's work internally and externally

The Health Services Management Centre has a similar resource to enable them to maintain their timeliness. They have access to a self-financing library service that is able to provide a similar service on a daily basis, the HMSC Daily Digest. The advantages to both Centres of this process are that they are up to date in terms of evidence and they are also in a position to be able to comment on findings or policy to the media. This information is used by the academics to keep ahead and to anticipate future direction for policy and research and enables them to respond quickly to announcements.

PHCRIS provide a similar service in Australia. The main difference is that it provides information of general interest to primary health care researchers nationwide and it is not specific to streams of research of academic departments.

PROCESS

POLICY/RESEARCH AGENDA

The relationship between the researchers and the policy makers is important if the policy research agenda is to be influenced. Both the NPCRDC and the HSMC work hard at maximising the opportunities to meet with policy makers and ensuring that they are fully up to date on the

developments in their respective areas of interest. The effect of this background work is to put them in a good position to respond quickly to requests for tenders or information. In addition to this, the researchers may be called upon to advise on new directions because the policy makers are familiar with their work and trust their opinions.

Specific examples of how the research policy agenda is influenced are:

- HSMC occasionally run closed-door seminars with policy makers to debate and discuss new policies and a change in policy direction. Policy makers are using HSMC as a store of "institutional memory" and expertise in the evaluation of programmes or policy.
- NPCRDC are funded by the Department of Health and as such must submit a 5-year strategic plan, which is then reviewed by the Department of Health. In this strategic plan the NPCRDC explore emerging policies and themes to be explored over the next five years. This plan also acts as a buffer to some of the change in policy personnel.

Increasingly gaps in the knowledge are being identified by organisations such as the UK's National Institute for Health Research (NIHR) Health Technology Assessment Programme. There is also a role for organisations such as the British Thoracic Society to convene a group to identify research and policy priorities in the field of respiratory medicine and present these to relevant stakeholders.

The HSMC has recently used its expertise to develop a new masters' programme in commissioning in health services in response to the increasing use of commissioning.

REPORTING

Researchers believe that policy makers should use evidence to inform policy but may not always present research in a way that is useful to policy makers. The Canadian Health Service Research Foundation recommended the use of the 1-3-25 report format for presenting research findings to policy makers and health service managers. Whilst most of the researchers and policy makers interviewed agreed that the 1-3-25 style of reporting was valuable several highlighted the greater importance of putting the findings into context, rather then a standard "off the peg" reporting framework. This is particularly important when considering the diminishing institutional memory in government. The policy makers highlighted the need for clear messages as the reports are often read or interpreted by intermediates and so it is important that the key findings are not attenuated.

Examples of more innovative forms of reporting are:

- "Spotlight…" approximately six pages and put the findings of the research into the wider policy context [18].
- 3-pager – produced as a stand-alone document for projects but increasingly they will only be available on-line [19].
- Briefing paper (1 –2 pages) – highlighting the key messages [20].
- Pod casts.
- Use of trade journals (Health Service Management Journal) and newspapers such as the Guardian (HSNMC).

The NHS Confederation has focused on providing answers to policy makers' questions and using this approach to help shape reports. For example using headings such as "what hazards should we avoid?" or "the NHS not listening to public opinion". In producing the shorter reports it is helpful to have people in the team who have journalism or communication skills to support the academic staff in moving away from traditional academic writing. In making the findings more accessible and briefer it is important to ensure s much is not stripped from the findings that the results become meaningless. It is important for academics to remember that people have different ways of knowing and that including a "story" to illustrate something in a report can be very powerful.

Policy makers and academics may be interested in the effect of a policy or intervention on different outcome measures.

Overall, academics often struggle with reporting the findings or research in a way that is useful to policy makers. Writing the reports for Stream 4 was a challenge and it was difficult to move away from the standard scientific format. Feedback from Australian policy makers would be useful to establish how relevant and useful the 1-3-25 format has been here and what format would be most appealing and useful to them in the future.

DISSEMINATION OF REPORTS

The dissemination of the report is important. Many of the organisations spoken to spent a relatively large proportion of their budget on communications. For example the NPCRDC spend approximately 10% of their total budget on communication, at the Health Foundation approximately 25% of the staff are PR or communications staff. The overall opinion was that there was no point producing reports or papers describing high quality research if they do not reach the end-users such as policy makers or health service managers.

Both the NPCRDC and HSMC have a mailing list so that hard copies of the short reports can be sent to key people. Whilst these reports are available on-line, the NPCRDC value the fact that a professionally printed document lands on a desk rather than a poorly printed copy of one downloaded from the Internet. Where possible, press releases articles for Pulse or newspapers were timed to coincide with the publication of research findings in a peer reviewed journal. The purpose is to maximise impact. The HSMC also make good use of the Health Service Management Journal and broadsheet newspapers. For both centres it has been important to contribute to inform policy whilst maintaining academic independence and rigour.

The dissemination process for the Stream 4 work has been difficult. Publication of the key findings of the reviews in a peer-reviewed journal has been a challenge for some spokes. The methodology was complex and not standard for systematic reviews and journals have been concerned about duplicate publication because the full report has been available online. This may not have had an impact on the way in policy makers have used the research but it has had an impact on standard academic outputs of some of the spokes.

SIGNIFICANCE OF THE FINDINGS FOR AUSTRALIA

Chronic disease management in the UK has drawn heavily from US managed care organisations such as Kaiser Permanente and have taken a multidisciplinary team approach to patient care, which has been successful. The Quality and Outcomes Framework has established that benchmarks can be met using a variety of primary health professionals. The challenge for Australia will be to embrace the increasing use of multidisciplinary team care with a funding structure to facilitate this. A key feature of many of the programmes and achievements in the UK has been the existence and use of high quality and comprehensive practice level data. Practice data of this quality and scope are not widespread in Australia. Support for practices to improve their practice level data will enable policy makers and health professionals to monitor the process and outcomes of care.

The environment in which policy makers exist in Australia is similar to that in the UK. There is frequent movement of staff that results in poor institutional memory and there is also a need for information quickly. The Australian policy environment is more complex than that of the UK because of the State and Federal levels of government and the different health needs and workforce issues that occur in urban, rural and remote areas of Australia that do not occur in a small densely populated country such as the UK. APHCRI is in a good position both geographically and academically to develop these strong relationships with policy makers and act as a repository of institutional memory. The hub and spoke structure provides a link between policy makers and a variety of experts. The only potential drawback of this model is that with this type of “brokerage” there might be less direct contact between spokes and policy makers and the UK experience demonstrates the importance of these personal relationships for effective linkage and exchange.

An integral component of the PHCRED program is Primary Health Care Research and Information Service (PHCRIS), which provides a variety of updates of different frequencies targeting different aspects of primary health research and policy. This is a valuable service for a wide range of academics and policy makers. A national service such as this was not available in the UK and the focus was on department specific updates. PHCRIS information is of general interest to primary care and it is still important for individual centres to monitor specific interests to enable academics to keep fully up to date in their field of interest.

Finally the evidence from the UK suggests that there may be reporting styles that are more effective and useful than the 1-3-25 style of report, although this has net been formally evaluated. Academics and policy makers should discuss their experiences of using the 1-3-25 report and explore whether there is a need to improve the report format or develop a new type of report for the policy making environment in Australia.

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