

Service Implementation - Do Once and Share

Renal Action Team

Final Report

Version 1.0

Date December 30th 2005

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Amendment History:

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Forecast Changes:

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Reviewers:

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Name	Signature	Title / Responsibility	Date	Version
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Approvals:

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Related Documents:

These documents will provide additional information.

Ref no	Doc Reference Number	Title	Version
1	NPFIT-SHR-QMS-PRP-0015	Glossary of Terms Consolidated.doc	6

Glossary of Terms:

List any new terms created in this document. Mail the NPO Quality Manager to have these included in the master glossary above [1].

Term	Acronym	Definition

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Appendices e.g Scoping Document, Output information, Project Plan

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4. Current Renal IT functionality
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ACTION TEAM: Renal
ACTION TEAM LEAD: Bernie Stribling
PROJECT MANAGER: Bernie Stribling
LOCATION OF ACTION TEAM: Leicestershire, Northamptonshire and Rutland
SHA LEAD: Dr Paul Cosford, Director of Health Strategy and Public Health
ACTION TEAM START DATE: July 1st 2005
DATE OF FINAL REPORT: December 31st 2005
1. BACKGROUND
The East Midlands Renal Network (EMRN) serves a population of 2.5 million people across the East Midlands to include Leicestershire, Northamptonshire, Rutland (LNR) SHA. Currently 1 tertiary centre, 4 DGHs and 6 satellite dialysis units provide nephrology services. To date the network has concerned itself with the management of end stage renal disease (ESRD). However it is now recognised that non dialysis dependant chronic kidney disease (CKD) is extremely common and that the real challenge for nephrology services is to provide appropriate care for these patients. This would include identifying those at risk of developing ESRD and attempting to delay progression, reducing complications of CKD and in particular managing cardiovascular risk, which is high in these patients. The majority of patients with CKD either do not require or can be prevented from needing treatment within a tertiary or DGH nephrology setting. This challenging aim can only be achieved by seeking to develop a patient care pathway, which is patient focused and bridges the traditional boundaries within health care provision. In particular it must integrate care across tertiary, secondary and primary care settings.
2. PROJECT OBJECTIVES
Develop a systematic approach to renal disease across primary and secondary care to help join up expertise and to reduce variation in care, making the best the norm. To reduce unknowing duplication and create national consistency, with local sustainability.
SHA EXECUTIVE SUMMARY Name: Dr Paul Cosford.
4. DETAILED REPORT ON WORK WITHIN SCOPE (any outputs from this work which are not covered as specific deliverables)
Output 1: - Provide baseline information on the current standard of clinical practice, and likely changes to clinical pathways which will result from ongoing work on chronic disease management, implementation of eGFR and changes in cross boundary flows following implementation of referral guidelines

<p>Status: Completed</p> <p>Date of Completion: December 2005</p> <p>Summary of findings: Current standard of clinical practice explored both locally and nationally. Baseline information of CKD within a practice population available at local level. At National level a greater understanding of clinical practice has been achieved and this has helped add to the renal patient pathway through “confirm and challenge” meetings. This pathway has formed the basis of the work profile and has helped create a platform whereby new ways of working could be introduced. Once such example is a virtual nephrologist service “Ask the Nephrologist” where clinical advice is provided by a specialist allowing timely intervention locally without the need for the patient to visit the tertiary centre. Implementation of eGFR reporting both locally and nationally will help drive the need to find different way of working, as well as provide an opportunity to allow earlier identification of CKD in primary care. Making eGFR available has created a need for clinical guidelines and education for all health care professionals. The patient pathway still requires patient and public involvement to ensure it achieves the aim of ‘Do Once and Share’ and is not repetitive of many clinical procedures between primary and specialist care.</p> <p>To include details of workshops/meetings which were held to enable National Stakeholder involvement and key issues raised at these events:</p> <p>See Appendix 1 Stakeholder engagement</p> <p>Evidence of national stakeholder sign off/ agreement:</p> <p>Development from a linear representation, to a comprehensive framework for management. After engagement at the <i>confirm and challenge</i> meetings current pathways now posted on BRS and Renal association website for ongoing dialogue.</p> <p>Appendices: Appendix 2. Care Pathways</p>
<p>Output 2: - Identify training implications</p> <p>Status: Ongoing</p> <p>Date of Completion:</p> <p>Summary of findings: The patient pathway which has been used extensively throughout this project under the banner of “confirm and challenge” has helped discussion around maximisation of existing roles, identification of new roles and new ways of working. It will be necessary within the pathway to explore the skills and competencies required through Skills for Health framework so as to create a seamless pathway for the patient without duplication. For the future migration of data, the current role of Renal Information Manager within many Nephrology units requires recognition, continued support and development.</p> <p>To include details of workshops/meetings which were held to enable National Stakeholder involvement and key issues raised at these events:</p> <p>Appendix 1 Stakeholder Engagement</p> <p>Evidence of national stakeholder sign off/ agreement:</p> <p>Not applicable</p> <p>Appendices: Appendix 1 Stakeholder Engagement</p>
<p>Output 3: Establish connections between patient pathways and the proposals for the map of medicine and the electronic library for health</p> <p>Status: Delayed</p> <p>Date for Completion: Not known.</p> <p>Summary findings: Both the map of medicine and the electronic library for health were not available for engagement by the completion of this project</p> <p>To include details of workshops/meetings which were held to enable National Stakeholder involvement and key issues raised at these events:</p> <p>Evidence of national stakeholder sign off/</p>

<p>Not applicable</p> <p>Appendices: None</p>
<p>Output 4: Outputs for SNOMED required</p> <p>Status: Delayed</p> <p>Date of Completion:</p> <p>Summary of findings: Health professionals in primary care are using READ codes version 2 and many in secondary care are currently using Clinical Terms version 3. Some key renal terms are not currently coded within draft versions SNOMED e.g. stages of chronic kidney disease (CKD)</p> <p>To include details of workshops/meetings which were held to enable National Stakeholder involvement and key issues raised at these events: Presentation from Grant Kelly at National DOAS Network event November 2005 identified no national agreed implementation date.</p> <p>Evidence of national stakeholder sign off/ agreement: Discussion with national stakeholders identified concerns around what codes will be available and concerns around mapping to MESH (Medical Subject Headings). The clinical result of this could be that a patient coded with CKD by SNOWMED could not produce decision support based on medical literature</p> <p>Appendices: None</p>
<p>Output 5: Describe the current functionality of renal IT systems, their current potential, and the expectations of the wider renal community for future systems, including any finished, or pilot projects in progress</p> <p>Status: Ongoing</p> <p>Date of Completion: Pilot completion December 2005. National completion March 2006</p> <p>Summary of findings: Through the Renal Information Exchange Group (RIXG), a description of current functionality of the various renal IT systems in the UK, their current potential, and the expectations of the wider renal community for future systems is being electronically collated and compared with the OBS for Renal</p> <p>To include details of workshops/meetings which were held to enable National Stakeholder involvement and key issues raised at these events: See appendix 1</p> <p>Evidence of national stakeholder sign off / agreement: Has been presented to RIXG members (membership appendix 8)</p> <p>Appendices: Appendix 3 OBS specification comparison. Appendix 4 Current Renal IT Functionality</p>
<p>Output 6: Develop communication plan between national renal community and NPfIT through "Confirm and Challenge" meetings</p> <p>Status: Ongoing</p> <p>Date of Completion: December 2005 as part of this project</p> <p>Summary of findings: The core action team have engaged widely both with the nephrology specialists, secondary care specialists and primary care. The meetings so far have spanned the UK engaging with nephrologists and the wider nephrology team, multidisciplinary primary care teams and other clinical specialists. The meetings have utilised the patient pathway as the basis for discussion with each group / discipline adding to this to ensure it is "all encompassing" of clinical needs. This has largely followed a 'Confirm and Challenge' approach and clinical decisions are then added to the pathway to help shape it. This is now a robust tool and has helped adopt new approaches to working including the "virtual nephrologist" concept</p> <p>To include details of workshops/meetings which were held to enable National</p>

<p>Stakeholder involvement and key issues raised at these events: Appendix 1 Stakeholder engagement</p> <p>Evidence of national stakeholder sign off of confirmation of agreement: Development from a linear representation to a comprehensive framework for management. After engagement at the confirm and challenge meetings the current pathways are now posted on BRS and Renal association website for ongoing dialogue</p> <p>Appendices: Appendix 2. Care Pathways</p>
<p>Output 7: Produce Guidelines for primary care on the implementation of the project</p> <p>Status: Complete</p> <p>Date of Completion: December 2005.</p> <p>Summary of findings: The project recognised the need to 'Do Once and Share' and as part of this a set of renal guidelines were adopted and modified locally from the National Guidance on CKD. These guidelines allow for interpretation at a local level with a facility for confirmation e.g. "Ask the Nephrologist". They also support the early identification of CKD amongst a practice population so that the patient with CKD can achieve best outcomes and not are limited on choice.</p> <p>To include details of workshops/meetings which were held to enable National Stakeholder involvement and key issues raised at these events: Appendix 1 Stakeholder engagement</p> <p>Evidence of national stakeholder sign off of confirmation of agreement: After engagement current CKD guidelines are now posted on BRS and the East Midlands Renal Network website for ongoing dialogue and sharing</p> <p>Appendices: Appendix 5 CKD Renal Guidelines</p>
<p>Output 8: Produce timely reports as identified by stakeholders</p> <p>Status: Complete</p> <p>Date of Completion: December 2005.</p> <p>Summary of findings: NHS Connecting for Health, RIXG and East Midlands Renal Network have all received timely reports on the projects progress. Presentations on the project were given at the DOAS National Network event and Clinical Leads for Connecting for Health in November. Reports have been tabled at the RIXG and EMRN and SHA meetings.</p> <p>To include details of workshops/meetings which were held to enable National Stakeholder involvement and key issues raised at these events:</p> <p>Evidence of national stakeholder sign off of confirmation of agreement: Project identified within the Delivery strategy for Renal Services September 2005</p> <p>Appendices: None</p>
<p>5. UPDATE ON PROJECT CONSTRAINTS and RISKS</p> <ul style="list-style-type: none"> • The renal dataset will not be complete until 2007. • Map of medicine not ready to engage with. • Electronic library for health not ready to engage with. • SNOWMED not ready to engage with.
<p>6. DETAILS OF ANY CONTINGENCIES IMPLEMENTED</p> <p>Despite the efforts of this project group, engagement of the above has not been possible.</p>
<p>7.. DELIVERABLES (progress report on all deliverables listed in the Scoping Document)</p>
<p>Deliverable name: Resources for eGFR and CKD staging in health care</p>

<p>Status: Completed Date for Completion: December 2005 Summary findings: For the implementation of eGFR and CKD staging in health care, a training programme encompassing eGFR guidelines, laboratory results now give CKD definition with test result, setting up EMRN web site which host the guidelines, communication to all GP's on three occasions, a mouse mat with the guidelines and demystifying renal disease presentations. To facilitate ongoing education, all inappropriate referrals are discussed with the referrer by a member of the nephrology medical team and sent a copy of the CKG guidelines. Since implementation this has occurred approximately twelve times. Stakeholder Consultation process: Appendix 1 stakeholder engagement Evidence of national stakeholder sign off / agreement: Issues: None Mitigations: None Appendices: Appendix 5 CKD renal guidelines</p>
<p>Deliverable name: Public and patient engagement Status: Completed Date for Completion: December 2005 Summary findings: In line with a patient led NHS engagement with both public and patients was felt to be desirable. We wished to explore where and how patients and the public accessed healthcare information what expectations of responsibility for their healthcare they held. Despite advertising efforts the turnout was disappointing. However, it was an important learning experience as the proposed engagement was early in the DOAS experience and Connecting for Health may need to revisit this aim to ensure public and patient engagement. Stakeholder Consultation process: Appendix 1 stakeholder engagement Evidence of national stakeholder sign off / agreement: Not applicable Issues: Issues around future public and patient consultation within a time limited framework Mitigations: None Appendices: Appendix 6 General Public Questions</p>
<p>Deliverable name: Choose and Book Status: Ongoing Date for Completion: Summary findings: Through the Renal Association representative, Dr Paul Rylance, the renal community have been circulated with a discussion document about Choose and Book. To date no renal unit has gone "live" with nephrology Choose and Book Stakeholder Consultation process: Meeting with Dr Paul Rylance, Renal Association representative for choose and book Evidence of national stakeholder sign off / agreement: Not applicable Issues: None Mitigations: None Appendices: Appendix 7 Renal Association Choose and Book document</p>
<p>Deliverable name: Kaiser Permanente Status: Completed Date for Completion: December 2005 Summary findings: An opportunity for the renal team to lean and share ideas on case management as identified through Kaiser. Several similarities were identified,</p>

as well as opportunities to develop IT systems that help manage chronic kidney disease in a proactive way through case management across primary and secondary care. This presented opportunities to develop IT systems to facilitate clinical care, and data management in a way that promotes cooperation across disciplines, and patients in partnership for positive health benefits.

Stakeholder Consultation process:

Series of meeting with Kaiser in southern California over a working week

Evidence of national stakeholder sign off / agreement:

Not applicable

Issues: None

Mitigations: None

Appendices: Appendix 5 CKD Renal Guidelines

8. ADDITIONAL INFORMATION & RECOMMENDATIONS

To include future areas of work to be considered which were not included or fully addressed within the project.

The Do Once and Share Project has proved immensely successful from a renal perspective. However to maintain its momentum and to ensure continued engagement across the renal community will need ongoing support and investment over the course of the Do Once and Share project. The renal community are cohesive in terms of IT development and already have various systems within nephrology units. It would therefore be useful to use the patient pathway as developed by the Renal Do Once and Share Team as an opportunity to engage further with the nephrology teams and to offer aspects of this pathway for piloting locally. This would offer valuable insight to Connecting for Health in terms of how well received the pathway is, and to also test its assumptions in real life.

- The current gaps between the OBS and the functionality as described by the Renal Do Once and Share Team should be explored within dedicated communities of practice. To consider models of practice (Kaiser Permanente and Salford Diabetes Care) which link primary and specialist care together with some biomedical markers so that a transfer of data between primary and specialist care can be achieved utilising an interface engine.
- To develop the “virtual nephrologist” so as to offer clinicians within primary care the opportunity of a virtual consultation via web based decision tools and e-mail links.
- To develop an effective “interface” audit tool bridging the primary care and specialist care sectors to be able to assess that consistent care is being delivered irrespective of where the patient is seen and ensure appropriate transfer/referral of the patient into specialist care and back out to primary care. This would also give an understanding of referral guidelines as to whether they are safe, and effective.
- To develop patient education as an integral part of chronic disease management (from a CKD perspective initially but with much wider application in the long run). This would require a comprehensive programme with Quality Assurance (QA) as an integral part of it and could learn from the DAFNE project, which is currently available at a National and local level for patients who have type 1 diabetes.
- To liaise with Skills for Health in terms of identifying competencies that are required for individuals to undertake management of chronic kidney disease and renal problems and develop the appropriate training packages which would be made available electronically..

As a team the Do Once and Share feel that the development of these proposals will be essential to help secure the longevity of Connecting for Health and Do Once and Share into it becoming a reality over the next few months and years. It will also offer Connecting for Health the opportunity of having "road tested" within clinical practice certain aspects of IT functionality likely to be developed through the LSP's.

9. CLINICAL LEAD COMMENTS & CONCLUSIONS

This report reflects the scale of the existing commitment within the Renal Community to progressing clinical care, and support this with effective use of IT. The Renal Information Exchange Group has already provided a multi-disciplinary forum to promote the exchange of ideas, and the commissioning and management of IT developments. This has resulted in such successful programs as "Renal PatientView" which allows renal patients to see the data held within the renal unit computer system via the Web. There are also areas of innovation with Nephrology units developing "Virtual Nephrologists", and promoting interactive guidelines and advice on Chronic Kidney Disease formulated by Renal Association committees and published via their website.

Sharing of information between primary and secondary care, and between different secondary care specialities is becoming part of the accepted future models of care of patients with CKD. There is also acceptance that care of patients with CKD must form part of the care for several other related conditions such as diabetes and cardiovascular disease. Treating these conditions together successfully will vastly reduce duplicated effort, but require robust clinical IT systems to support the process. Several centres are actively looking for the technological tools to reproduce successful systems such as the Salford diabetes information sharing system where primary and secondary care share diabetes information via a shared database and web-server.

The secondary care renal community have access to well developed clinical computing systems which in some centres could more accurately be described as a EPR. There is understandable concern that this local development will be lost if an inferior LSP system is imposed, and that skilled Renal Information managers will be lost in this change. The exact functionality in these systems has been described in seven sites as part of this project, and the RIXG will go on to complete this exercise by asking all Renal Units to describe their systems.

The renal community remains committed to progressing clinical care through effective implementation of Information Technology and would wish to lead this process wherever practicable.

10.. Do Once and Share PROGRAMME COMMENTS

SIGN OFF

SHA Lead	
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Signature:	
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