**Coordinate My Care: A Research & Innovation Platform**
Proposal January 2018

## Introduction

Coordinate My Care (CMC) is a digital clinical service enabling any patient to have an electronic urgent care record. The service is linked to major hospital and GP electronic records systems (EHR), with the ability to be linked through NHS Digital to national datasets including the Office for National Statistics (ONS) and Hospital Episode Statistics (HES).

As an urgent care platform, CMC has a legitimate clinical role in an extensive range of patient populations, from those with malignancy, to non-communicable disease, and crucially, those on clinical trials. As a platform, CMC is adaptable and open to modular extensions. For example, the MyPain application, developed at the Royal Marsden Hospital, is being integrated with the system such that patients can record and analyse their pain remotely, sharing this data with their physicians.

To deliver better value healthcare, extensive research and development is funded to develop e-health applications. The current development model in e-health is to fund the creation of a standalone platform/web-service/application, and in some cases to then attempt to link these to EHR, before marketing the application and deciding upon a funding structure. This model suffers from significant costs, barriers to entry, time-lags, a lack of suitable professional expertise as well as challenges in uptake, financial sustainability and data governance.

Clinical trial management requires researchers to negotiate data governance, develop tools (or pay to use commercial electronic CRM platforms) to monitor patients, and research staff to record outcomes. Few studies have been able to take advantage of existing clinical networks to design and run large clinical trials, however, where it has been done using electronic registry systems, the costs have been approximately 1/10$^{th}$ that of conventional studies with no loss to follow up[1,2]. CMC, as a clinical service already linked to major datasets such as ONS and HES, could allow the UK to pioneer a more efficient, better value, trial framework.

This briefing document outlines a concept to extend CMC as a research and innovation platform, overcoming the deficiencies of the current e-health model and delivering a step-change in the efficiency with which we conduct clinical trials.

## CMC: A Research & Innovation Platform

Our vision is to develop a CMC Research & Innovation arm. CMC will develop the capacity to:

- Incorporate modular extensions in the form of electronic health applications, before prospectively testing their use.
- Act as a prospective research trial platform for cohort, randomised controlled and randomised registry trials.
- Release trial-proven electronic applications across the entire CMC platform for their use by suitable patients. This would enable CMC to act as a repository of NHS-approved apps such that both patients and clinicians could both

**CMC R&I: E-Health**

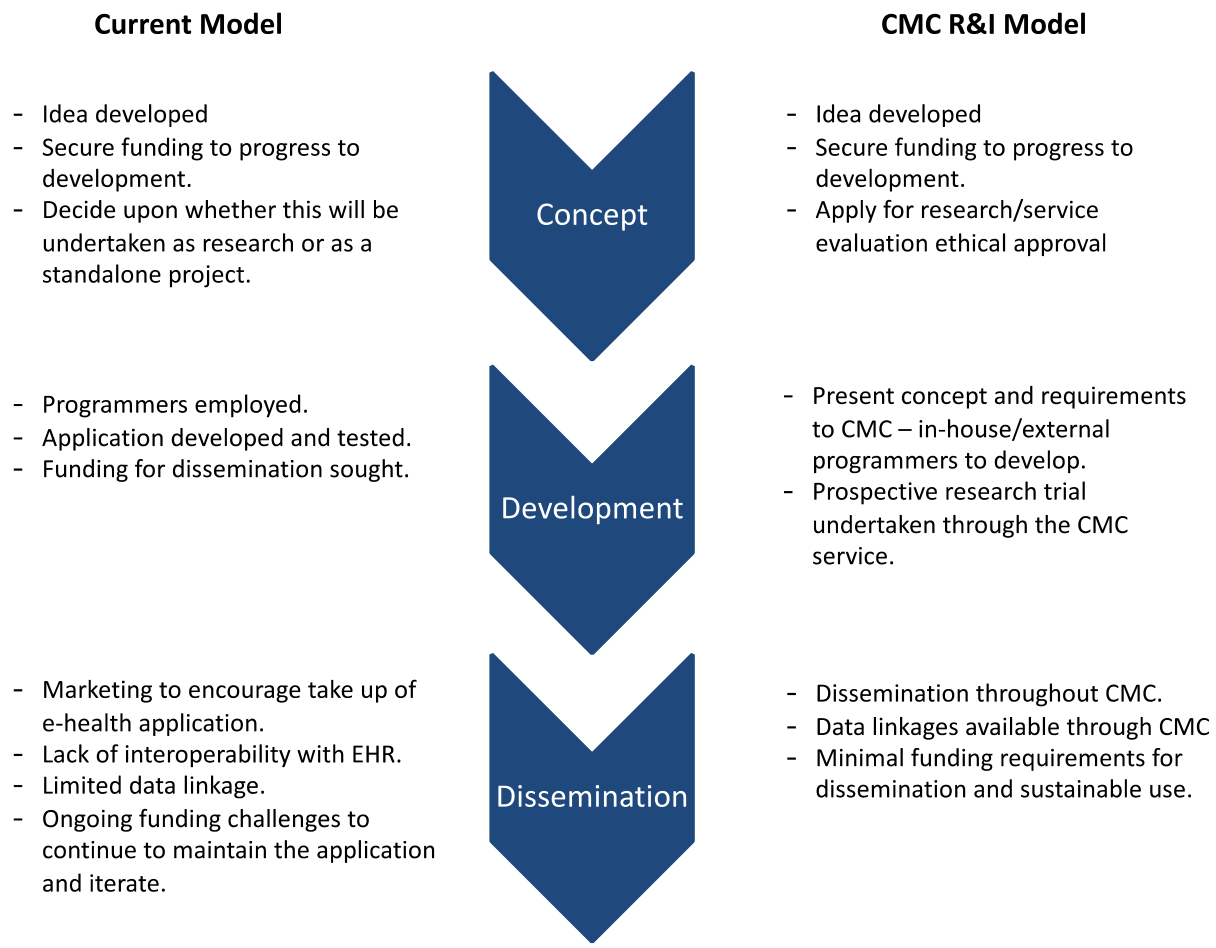


Figure 1: Current e-health app development & CMC R&I approach compared

CMC R&I has several benefits in the development, testing and deployment of e-health applications:

- Reduced costs, both in development, and through efficient dissemination of evidence-based applications, to the health service.
- Increased interoperability between applications and EHR.
- Tested data governance structures.
- Scalability.
- A repository of evidence-based NHS-approved e-health applications.
- Faster development and dissemination of evidence-based applications.
- Standardised patient-level data as required by the ICMJE in the publication of randomised controlled trials.

Case Example

*Researchers at Oxford University obtained NIHR-funding to develop an e-health platform to remotely monitor patients with heart failure by recording their symptoms, blood pressure, and medications. The hypotheses were that such a system might reduce hospital admissions, increase the proportion on evidence-based management, might enable a cardiologist to support GPs to deliver care to a significantly larger population remotely, and potentially reduce mortality.*

*To test this system, they needed to hire software engineers to build and manage the platform, comply with data governance, and link the platform to hospital/GP records. The platform requires a patient to answer a few questions every few days, ensure their medications are correct, and measure their blood pressure using a commercially available cuff. Subsequently patients were recruited prospectively from hospital outpatient clinics to one of two arms.*

*This project took almost 18 months to hire engineers and build the platform, and another 12 months to link the platform to EHR in the local area. Were the research to prove the effectiveness of the software, disseminating this and ensuring widespread uptake would require additional ongoing funding, the creation of an organisation to maintain the system and continue its link with EHR whilst expanding its usability across the country.*

*With CMC R&I, for a smaller cost given the economies of scale available by using in-house programmers, a modular unit could be built within the CMC platform that enabled the collection of the required information in a fraction of the time. Data links to EHR would already be available through CMC to many required sites, and additional sites could be added as needed. Outcomes such as mortality and hospital admission would be available from ONS and HES directly, reducing the number of administrative staff and research nurses per project. Dissemination, were the results to support it, could be automatic through the entire CMC system without requiring ongoing funding structures. This would lead to reduced costs, faster research results, and sustainable business models for these electronic health applications, providing better value healthcare for the NHS.*

**CMC R&I: Research Trials**

CMC could act as a research trial management platform. By employing its data links to national statistics, as well as its ability to incorporate modular extensions, CMC would be able to provide access to a larger pool of patients at a smaller cost with a diminished risk of loss to follow up (no risk if the outcome was death or hospital admission).

CMC R&I's role as a clinical research platform is best illustrated with some examples:

*In 2016, Maas and colleagues[3] published the results of a study into the utility of genetic data and epidemiological risk factors in identifying women at risk of developing breast cancer. In total, they used data from 8 large prospective cohorts of patients who had provided genetic data and ongoing epidemiological questionnaires (BMI, smoking, drinking etc) combined with external GWAS studies, the US National Cancer Institute-Surveillance, Epidemiology and*

*End Results Program, the National Health Interview Survey and National Health and Nutrition Examination Survey.*

*Each one of these cohorts and surveys will have been individually funded, be long-term in nature, costing millions of US dollars to maintain. With CMC, all these patients could be given a record at a fraction of the cost given the existing framework and infrastructure, with genetic data either linked to CMC or collected prospectively through the creation of a purpose-built module on the platform, and any epidemiological data could be filled in when required by alerting the patients that a survey had been posted for them on CMC. Through CMC, these patients would then be prospectively followed up with outcomes data available through HES (for first time diagnosed with breast cancer in this scenario) and mortality data from ONS.*

*A challenge faced by medical oncology is the evaluation of TKI-inhibitors and immunotherapy given the pace of change. Some cancers now have first, second, third and fourth line chemotherapy regimens where only one line existed ten years ago. Many of these novel therapies have not been tested against each other and therefore their true efficacy is unknown. It is not in the interests of pharmaceuticals to compare some of these therapies head-to-head and consequently funding is absent. However, with CMC R&I, all patients on trials for a cancer could be followed up at a marginal cost with outcomes data through ONS and HES, with the resulting prospective longitudinal cohort studies run through this registry-system enabling the evaluation of these therapies in the absence of prospective randomised controlled trials.*

These case studies provide just some examples of the potential use for CMC R&I.

**REFERENCES**


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