Informatics in health and aged care: a research program to support strategy development and implementation

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Abstract
There is renewed interest in the application of information management and technology to health and aged care in many countries including those in the Middle East. Strategy development has anticipated a range of benefits to health from the application of IM&T. Information strategies in health have sometimes been problematic. While many of the technologies that have recently attracted attention emerged some decades ago the barriers to their wide-spread adoption requires further research. Desktop-based systems have not always been well adopted in healthcare and there is an expectation that more recent innovations such as mobile technologies may better suit the work-practices of these and other mobile clinicians.

There is a need for assistance in the practical steps of evaluating technology, development and implementation of information standards, encouraging and enabling adoption of IM&T, and the development of rigorous financial cases for investment incorporating how benefits aims to be realised. There is also a need for the development of specific strategy for information management in aged care. All of these require a stronger research base including the development of methodologies, experimentation and learning through demonstrator projects.

This research in progress paper outlines an active research program for health informatics with a particular focus on aged care that has been developed in collaboration with researchers from Japan, Australia, New Zealand and other countries to support the development, implementation and evaluation of IM&T.

Keywords: e-Health, health informatics, information technology

1. Introduction
The Centre for Ageing and Agedcare Informatics Research (CAAIR) is an emergent consortium comprising research centres and researchers from Australia, New Zealand, Japan and other countries. This paper reports on its development and outlines the research program. The Centre for Ageing and Agedcare Informatics Research (CAAIR) aims to enhance care and independence for older persons and control increases in health and aged care costs through research and innovation in information management and intelligent technology. Achieving world class aged care is a major policy direction emphasised in the National Strategy for An Ageing Australia. The Centre will address a key goal of this Strategy, namely: “A care system that provides integrated and coordinated access, assistance and information for older Persons with multiple and significant and diverse care needs” 1. The Strategy states that “health and aged care information has a crucial role to play in quality improvement through the management of information on care standards, complaints and consumer rights”. Research and development is vital to “improve the management of patients’ care by improving the flow and linking of individual patient information”. Highlighted areas of focus in the Strategy include: data comparability and linking for service planning, data on service need and patterns of services. The CAAIR Research Program addresses these needs and opportunities.

Operating as a virtual centre across geographically dispersed nodes, the CAAIR links and builds upon its national and
international partner centres and aims to be the leading centre for information management and technology research for ageing and aged care in the Asia-Pacific region.

There is a need for the potential benefits of technologies in providing support for older people to be evaluated. This potential includes managing activities of daily living, supporting families as carers and advocates through technology such as remote monitoring, improving access to service delivery information, enabling clinicians to share care plans and better coordinate care. There is potential through technology to support ageing in place and reduce institutional care. There are expected to be large savings from applying technology to foster prevention and early detection of the onset of disease or disability, when treatment is often cheaper and more effective.

2. Approach
An Aged Care Informatics research program was developed over a 12-month period in consultation with participating research centres. A common interest was that the societies in each of these countries are ageing and there are concerns in each of the countries about potential impacts on their economies and health systems. Participants included the Collaborative Centre for e-Health at the University of Ballarat, Australia, Niigata University of Health and Welfare, Japan and the Centre for Health and Agedcare Informatics, University of Southern Queensland, Australia. The approach involved consultations which produced a draft Research Program which was then further refined through iterations of consultations.

This research approach undertaken in this study was designed to capture a cross-sectional snapshot and a dynamic longitudinal picture of the acceptance of idea of CAAIR and its applications to wider communities. The data were collected from stakeholders of various healthcare agencies about their opinions on the concept and projects that are applicable to wider communities. While many techniques are available to capture perceptions and attitudes of ideas of establishing a new initiative such as this, we employed an interview technique. This approach was employed in order to elicit open-ended responses to obtain factors that are not constrained by a pre-determined identification of constructs found in traditional surveys, as well as to determine the importance of the pre-determined factors. Given the relative newness of the idea, this technique was considered appropriate. Then a broader cross-section of samples was contacted to understand the changing views and behaviour pattern of stakeholders in order to ensure there is cohesion among members.

The instruments used in collecting opinions constituted two broad categories of questions. The first category of questions related to the appropriateness of CAAIR in a broader framework. The second category consists of potential applications that can be maintained under the umbrella of CAAIR. Open ended questions were included in the instrument to obtain unbiased and non-leading information. Prior to administering the questions, a review was conducted on the various questions asked in order to ensure that there was no bias and to eliminate any political sensitivity. Further, a two stage approach was used in administering the instrument, where the first stage gathered information about the key factors influencing the idea and the second stage on the importance of these key factors. This approach was deliberately used in this study in order to complement the open ended questions so as to determine the importance of the individual factors determining the shape of CAAIR.

The instrument developed for this process elicited responses of 'how' and 'why'. This was deliberately done in order to discern differences between various stakeholders as there was a range of opinions as to the formation of the centre. Further as the centre consisted of stakeholders from overseas countries, it was important to understand their views and then to accommodate them so as to glue the themes of the centre. In addition, responses obtained from various stakeholders were compared to ascertain that respondents were reporting their vision and current needs and not simply their current policies or challenges. Data obtained in this manner were analysed both manually and using a computer software application to arrive at a number of application themes that will drive the centre and a number of policy statements that will define the scope of activities of the centre. The following sections provide an overview of the research scope and research projects that were established as a result of this approach.
3. Research Scope

The iterative process of consultation with key researchers and other stakeholders resulted in defining the scope of the centre with the following streams:

(1) research and development of **technologies to assist in the delivery of health care into patients’ homes**, community care settings and care facilities by direct support of patients and carers, as well as supporting clinicians in these settings;

There are several developments and pilot studies involving a range of available technologies and devices include web-cam and other wireless devices to enable telehealth; monitoring devices including those for alerting of falls and tracking movements of elderly patients who may be at risk of wandering.

(2) addressing diversity through applications that focus on **rural and remote** populations, including ethnic minorities and older people in metropolitan areas with limited mobility or support systems. Technologies are being developed to allow the frail aged to remain in their own homes for longer, to delay or even avoid hospitalization or institutional care. These may reduce the need for travel and the use of inpatient facilities.

Further work is needed on packaging available technologies to facilitate adoption, particularly by the elderly in their homes and by time-constrained clinicians and other carers.

(3) research and development of **clinical decision support technologies**, software intelligent agents such as the digital Personal Care Assistant, and remote communications to link specialist and health care workers in the field. User-interface technologies aims to be linked to international databases to deliver timely evidence-based information;

(4) research and development of **tools and methodologies** to assist the health care industry in adopting a strategy-driven and standards-driven approach to IM&T investment. A standards-driven approach needs to ensure the ease and accuracy of information exchanges in health care, and between aged care and other care sectors such as hospital care and primary care. Information standards are needed to enable devices, software and databases to communicate and needs to impact safety, quality and efficiency;

(5) delivering **educational** products for students, clinicians, consumers and families;

(6) providing support for **national health information strategies**.

The scope specifically covers:

- Nation-wide consultation on priorities for information standards in health care
- Alignment with and contribution to international information standards development
- Development of the key information standards for health care

While efforts are currently underway to develop national health information strategies there is a need to share the experiences and methodologies, particularly where efforts have been successful. A lack of national strategy leaves some countries at risk of making IM&T investment decisions that are not guided by strategy. A planning framework needs to assist in prioritising investment and in directing resources to achieve benefits aligned with strategic directions.

4. Research Projects

a. **Electronic Health Records**

Research projects will investigate issues associated with data access and how this can be improved in order to facilitate better quality of service to consumers, carers, clinicians, families and managers. The research will focus on communication between stakeholders, the use of Internet and other technologies to address issues currently challenging aged care:

- **Accuracy and currency of patient records**: Inaccurate records are often the result of poor information sharing among stakeholders. There is often a presumption that the needs of aged care are a subset of hospital or primary care. Anecdotal evidence is that attempts to implement hospital or primary care information systems into aged care have failed. This supports the views held by the researchers that aged care is unique and that systems cannot be developed until there has been a thorough requirements analysis. Improved sharing of accurate and relevant clinical information is the goal and issues associated with clinical information sharing specific to aged care aims to be explored.

- **Integration of client records**: The goal is to achieve progressive electronic individual consumer/client records (**e.g.** admission
data, assessment records, care plans, care management charts and progress notes). Issues associated with the introduction of electronic client records, such as integration into workflow, aims to be investigated as well as the impact on care quality.

- **Decision-making**: Potential solutions aims to be investigated to overcome the problem of over-burdened care staff through projects involving intelligent software, including the emerging field of digital Personal Care Assistants and Clinical Decision Support Systems. Current research in aged care highlights the need for intelligent software to facilitate decision-making and care delivery, for example, reminders, monitors and alerts.

- **Infrastructure for aged care systems**: Health Online, and its HealthConnect projects, is the major infrastructure investment in Australian health information. This will provide an infrastructure that aged care will need to connect to for building and maintenance of the Electronic Health Record (EHR). CAAIR will research the interfaces and standards so as to ensure that aged and community care can take full advantage of HealthConnect and be a significant contributor and user of its information.

- **Use of information technology by older people and their families**: Barriers to the adoption of ICT such as insufficient education and support will be researched. Other issues, such as cost, access, equipment design and jargon, aims to be researched in order that older people gain confidence and access to this technology. A major question to be addressed by research is the extent to which dissemination of information and services can be reliant on electronic delivery without marginalising certain groups of older people.

- **Security and privacy issues**: These aspects aims to be an intrinsic part of the design of software, hardware and database products of the Centre and inform strategic and policy development at a national level.

### b. Capacity to measure quality care improvements

Access to and sharing of accurate and relevant clinical information is essential to the quality of aged care. Research is required to demonstrate the benefits of ICT in aged care covering:

- **Data capture**: Data capture impacts the quality and completeness of patient records which play a vital role in assessment and care provision. Research is urgently needed in this area for improving the quality of data capture and ensuring the currency of records. This will involve requirements engineering, work-flow analysis and user-interface design and include pre- and post-intervention audit of data entry activity, use of past and current data sets in assessment procedures, care planning, decision-making and care plans.

- **Communication of care requirements**: Communication of care requirements in residential aged care is an increasing focus of concern and the subject of a current ARC linkage project being undertaken by Prof Bartlett and her colleagues. It is not only an issue of the content of the communication (i.e. medical history, medications, care plans, dietary requirements, risks and alerts), but the structures and processes of communication. CAAIR will complement this through research into the potential of informatics for improving clinical decision-making, care planning and communication of care requirements.

- **Translating evidence into practice**: While examples of evidence-based practice in informatics can be found in the aged care and other sectors, translation of this evidence more widely has not been achieved to improve evidence-based decision-making. Research aims to be conducted by the Centre to improve the evidence base of aged care service planning and delivery. Several researchers are already working in this domain.

- **Records and audit trails**: Studies aims to be undertaken to examine issues associated with ‘transparency’ of records, including the ways audits are conducted and compliance adhered to. Research will explore improving accuracy of audit trails of assessment data, decision-making processes, workflow, and impacts on care interventions. While this activity aims to be challenging at the aged care facility level, researchers will work closely with sector representatives, Commonwealth and State
departments to develop a framework based on best practice.

- **Referrals**: Timely referrals for specialist consultations are facilitated by progressive, accurate and timely data sources. Combining modern technology and accurate assessment procedures based on high quality information, it is possible to provide timely referrals for specialist care. Studies will focus on issues associated with this approach, such as automated referrals and alerts to save lives, time and money.

  **c. Efficiency, productivity and quality**

  Research activity within this thematic area will concentrate on reducing paperwork, simplifying monitoring and reporting, and on report-generator engines to assist providers in reporting to funders and regulatory authorities. The research of the Centre will focus on reducing paperwork and improving efficiencies. Projects will address:

  - **Paperwork**: A common complaint on the part of providers is a perception of a burden of paperwork, detracting from client care. Despite exploration in various forums there is not yet a solution. Projects will gather metrics, review workflows and analyse the level of paperwork to identify opportunities for process improvements as well as opportunities for automation. This will include examination of availability of reports on individual and aggregate consumer/client data sets, *e.g.* reporting incidents/accidents, restraint use, infections, hospitalisations, medical consultants, to identify consumer/client profiles and trends.

  - **Exception reporting**: This is required to identify unexpected changes in consumer/client profiles and to increase accuracy of human and other resources required for increased/reduced care requirements. The generation of exceptions would benefit the aged care industry by aiding the re-distribution of human resources. Projects will explore effective ways of achieving exception reporting and measure the benefits.

  - **Application of available consumer/client information in decision-making**: This is highlighted in the previous section with a specific focus on information management. It is conceivable that using current technologies, it is possible to achieve efficiency gains in many areas including decision-making.

  - **Multidisciplinary care planning and decision-making**: Research will explore the use of communications and information technology to assist professional groups, carers and families in participating in care planning and decision-making.

  **d. Innovative technologies**

  With the increasing cost of providing rural and remote patients with consultations that can only be provided by metropolitan agencies, there is a necessity to research and evaluate innovation that may control costs. The following are the themes that are being followed:

  - Remote consultancy services and computerised assessment forms
  - Access to geriatric and gerontic expertise in rural and remote Australia
  - Monitoring and other intelligent devices for home and community settings.

  **e. Information standards**

  There is a major need for development of information standards for aged care. While there is a national strategy in healthcare, there has been little work on the requirements and priorities in aged care. Information management and systems must be guided by standards to ensure linking and sharing of information, to ensure there are common meanings so as to avoid errors, and to reduce duplication of data entry and storage. Technologies that conform to standards are likely to have a longer operational life as in the example of the videotape standards of Beta and VHS. These standards need to be aligned with international developments. Australia is leading several of the major streams of work within Health Level Seven (HL7) – the major international health information messaging standard. HL7 has been endorsed for the Australian healthcare sector. CAAIR Projects will include:

  - Nation-wide consultation on priorities for information standards in aged care
  - Alignment with and contribution to international information standards development
  - Development of the key information standards for aged care
5. Research program
CAAIR will undertake research to guide information strategic planning and economic analysis to inform investment decisions, requirements engineering, information standards development, integration of existing technologies, evaluation of technologies and the development of products to address gaps in market offerings.

Reasons for the low investment in ICT in aged care aims to be researched including funding, the availability and suitability of products, the need for requirements engineering, and the level of confidence in realizing the anticipated benefits. The CAAIR Stream 5: Strategic and Economic Analysis will research tools, methodologies and templates to assist in strategic investment on ICT in aged care. This will include education and training.

There are a small number of devices emerging that will assist in tracking patients, providing falls alerts and medication reminders. There is a need for research into why the adoption is slow and the need for additional or superior devices to facilitate independent and active living in situations that in the past would have necessitated institutional care. There are increasing numbers of on-line services including on-line patient personal health records, monitoring, consultations, and medication purchasing. Software Personal Care Assistants could link with these and with in-home devices and provider-based health records providing much-needed integration of information. Nevertheless, the deployment of devices is slow. This may be due to doubts about the benefits, the suitability of the devices, the user-interfaces or the integration with other systems. Research stream 3: Innovative Technologies will research these factors, will develop interface engines to better integrate existing technologies and will develop devices to fill gaps. The approach aims to be to use “off-the-shelf” components so as to maximise affordability.

CAAIR will develop guidelines, methodologies and standards for informatics in aged care to ensure their successful adoption and to realise anticipated benefits. The policy and funding barriers to exploitation of ICT in aged care aims to be researched and recommendations made to relevant authorities. CAAIR will usher in a new environment of “plug and play” to fast-track the adoption of ICT in aged care.

6. Strategic and economic analysis
While efforts are currently underway to develop an Australian Aged Care Information Strategy, the current lack of national strategy combined with the “cottage-industry” nature of much of aged and community care leaves the sector at risk of making ICT investment decisions that are not guided by strategy. A planning framework will assist in prioritising investment and in directing resources to achieve benefits aligned with strategic directions.

CAAIR will develop a methodology and templates specifically for use in aged and community care to assist in the development of information strategy and as a guide to making ICT investment decisions.

The Centre will undertake economic models to better research the benefits and barriers to ICT investment. It will produce an economic analysis tool and templates that can be used by aged care institutions to develop and project their investment status.

7. What is the Next Step?
The scope of the centre and the research projects provide an initial impetus to start activities of CAAIR. However, at the time of writing we are not able to scope individual projects with deliverables and their alignment to meet various national and international objectives. This is currently being undertaken with stakeholders in Australia and overseas. The main objective of undertaking this task is to scope individual projects and seek support from appropriate industry partners in order to obtain appropriate resources to complete these research projects. Currently two projects are being negotiated with specific deliverables and associated process. CAAIR has also attracted PhD and Masters’ students in 2005 Australian academic year to realise its dreams and visions. The University of Southern Queensland has already funded Aus$170,000 to construct a wireless research laboratory that can be utilised by CAAIR to conduct research and the local health district has indicated support in terms of other resources. Currently grant applications are being prepared for national competitive grant schemes to attract funds.

8. Summary
This paper reports on the development of the CAAIR Research Program which was developed
for health informatics with a particular focus on aged care. The CAAIR consortium is an open one that aims to share its outputs and engage in dialogue with others working in this field. It is expected there will be links with the Middle East through the newly-opened campus of USQ in Dubai as well as a recently opened dialogue with the Royal College of Surgeons, Edinburgh which is around collaboration in education and research.

While ageing is not yet an issue in most Middle East countries, in almost all countries, aged persons consume a disproportionate share of health services. Consequently the outputs of CAAIR are expected to have broader applicability.

The consortium operates as a virtual centre which will facilitate sharing and exchange of approaches to informatics to support ageing in place and reduce institutional care. There are expected to be large savings from applying technology to foster prevention and early detection of the onset of disease or disability, when treatment is often cheaper and more effective. Researchers and policy-makers are invited to be joined to the initiative through the Address for correspondence below.

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9. References


