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A Patient Care Electronic Diary to Empower the Patient and their Virtual Care Team

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Abstract: E-health is a dynamic and increasingly important support to health care services, and indeed is stimulating new patterns of provision, though in many respects it is supporting traditional attitudes to service delivery. However, the new agenda in Europe is for truly patient-centric care, and for support to people not only in their own homes, but within normal lives. This needs a new paradigm of thinking about health care delivery, from patient-as-recipient to person-as-focus. Care delivery needs to be planned to fit the person's life schedule. It also needs to be coordinated across different professional and service strands, and to be delivered as promised, not as hoped. Informatics concepts and services common in other service industries, such as electronic diaries and management of time resources, together with modern communications and devices, could radically improve the pattern and quality of support from within the same professional resources. However, this requires both an integration of different technologies, and a paradigm shift in health sector thinking. This paper outlines the vision and the desirable next steps,

Keywords: eHealth; patient-centred care; care scheduling; care delivery; care diary

1. Introduction – Moving to a Patient Focus

The health sector in the United Kingdom, and in many other European countries, has recognised the need to move from organisationally-focused working to a patient-focussed approach, frequently referred to as patient-based care, or patient-centred care. However, all too often this is still centred within the individual health care provider organisation, with each care provider either referring the patient to the next one for assessment, treatment and support, or hoping (as opposed to having evidence) that an external virtual team can be assembled to provide integrated support.

A concurrent challenge is that increasingly and appropriately, health care is being delivered to citizens in their own homes. New forms of treatment, earlier hospital discharge, and integrated community services are enablers of this. Moreover, as longevity and survival of chronic diseases increase, these successes of healthcare and societal progress mean that there are more citizens with complex needs requiring healthcare and social care help at home. Thus the health care sector is presented with the challenge of providing a higher level of health care treatment and support in a domiciliary setting, with that support being more complex; often with parallel co-morbidities; meeting increasing pressures on treatment and formal care providers; yet at the same time operating within an increasing consumer expectation of quality, personalisation, and reliability.

Parallel to this increasing healthcare delivery challenge, information science is increasing its support to the health sector proactively. E-health is an increasingly recognised enabling technology, but its particular foci are currently on electronic patient records, and on remote services and sensing. There are other well-established automated processing techniques such as time resource management, scheduling and planning, of which the health sector and its ehealth support have made comparatively little use compared to other service industries. At the same time, Information and Communication

Technologies (ICTs) are developing rapidly, enabling concepts such as fine grain access control, and multiple forms of front end interface, to provide much more intuitive data entry and data display. This paper discusses how currently available information processes, software services, and interface technology should be harnessed to provide a new paradigm in efficient and effective patient-centred care delivery and assurance.

2. Patient-Centric Care

Citizens with ongoing health needs wish to live an optimal and autonomous life commensurate with their particular health status and challenges, and not be seen as lifelong patients. However, this needs a further paradigm shift in health care delivery, from multiple providers treating the citizen as a patient with a specific health problem at home, to one in which providers realise they are contributing to a citizen's totally integrated and personally influenced cross-organisational pattern of support - namely cohesive patient-centric care, with the citizen having an input into that pattern. Figure 1 shows the change in mind-set and organisational focus needed – the actual care delivered being the same.

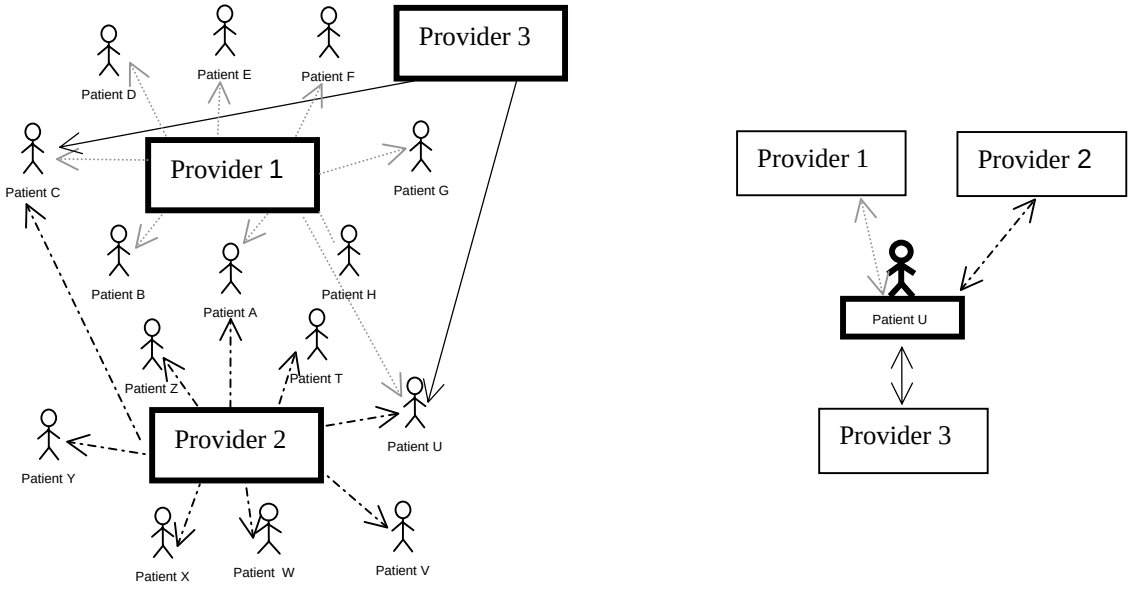

Figure 1: The Paradigm Shift to Patient-Centred Care

The concept of the extended 'virtual' team, focussed around the patient, was raised some time ago in the context of primary care electronic records [1]. In this concept each 'virtual' team would be customised to that patient and their health needs whilst working and being accountable within their normal organisational setting; electronic records and shared access would be the factor providing co-ordination and cohesion. However, realisation of this vision has been slow, not least because of the diversity of organisational-specific systems.

3. Objectivity and Availability of Care

3.1 Care Objectivity

Concurrent with the development of this vision was research into the design of community health record systems, emphasising that care should be objective based using care planning

principles. Using these principles care is provided to meet a specific need, and is also provided against both specific care goals and a medium- or longer-term holistic strategic aim for the individual [2, 3]. This has resulted in a published conceptual framework for care delivery as shown in Figure 2. Not only does this inform the patient (and with their permission, their next of kin) of the major and purpose of the treatment scheduled, but it means that all care workers will be similarly informed. This is particularly valuable where co-morbidities exist so that two teams of care providers should be working to common goals; it is also invaluable where new or locum members join the virtual care team.

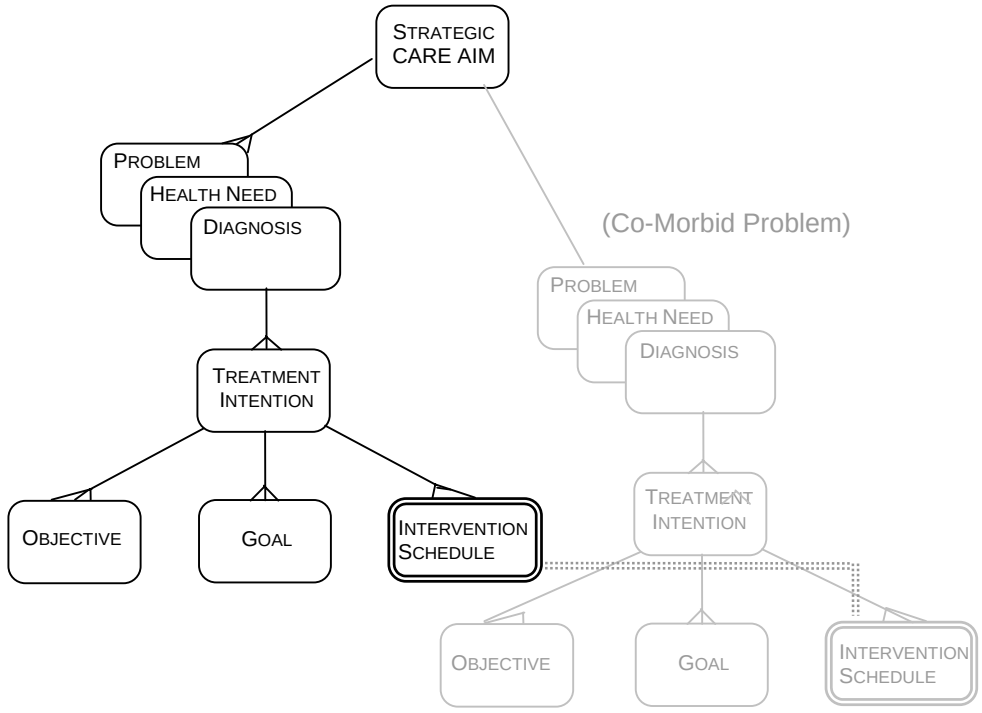

Figure 2: Objective Care Planning (after Robins and Rigby [2])

If this is in place, using reliable electronic scheduling systems, a new paradigm in healthcare delivery and reliability becomes possible [4]. It should mean that whenever a health professional is called in, or has a patient referred to them, they know not only the purpose of the contribution, but also the depth or limitation of their mandate – giving an assessment and opinion leads to very different depth of results from providing a therapeutic intervention within a particular ongoing programme of care, yet without an adequate briefing including the nature of the mandate the individual carer can provide inadvertently a quite inappropriate depth of intervention or type of response.

3.2 Care Availability and Reliability

Further, for practical, ethical and moral reasons, inter-disciplinary care should not be promised to the individual unless it is know that it can be delivered – and this means ensuring that the partners have availability of resource to the required pattern. However, under current patterns of healthcare and organisation and provision, the health professional recommending or requesting a particular pattern of care seldom has time at that moment to make enquiries and ensure that the service component is available and to an appropriate timescale. It may, for instance, be desirable to have a regular visit to a day hospital, a fortnightly home visit by a nurse, and physiotherapy delivered at weekly home, together with an assessment of the mobility suitability of the house: if one element is unavailable the balanced care package is compromised, while if all providers offer the same day of the

week the balanced delivery is impossible. All too often, the prescribing practitioner has to advise the patient that they will hear in due course when the service components will be provided – a situation which is unsatisfactory for the ill or dependent person, and inefficient if the individual components or virtual team members are not able to synchronise effectively. Moreover, it puts the dependent patient in the difficult position of having to try to negotiate a change in schedules.

Moreover, once promised, care delivery should be reliable. Commerce and industry already consider resource management and scheduling normal – indeed essential – requirements using modern time management concepts and related computing methodologies, but this is still seen as revolutionary in health and social care [2, 3]. If e-health really is to be provided to citizens, in an integrated way using a virtual team, then the health sector needs to catch up. Being able to search partner resource availability, and use automated resource management and scheduling tools, would achieve this.

4. A "CareBook" Approach

For these reasons, a new "CareBook" philosophy based on availability of reliable internet services is proposed. This would make a citizen electronic diary the prime vehicle of all care planning and care delivery, and would enable contextualisation of formal care with other important elements such as regular family member visits, or social interest groups. Service providers would have access to this, so that it would be far easier to ensure that different health and social care supports did not cluster or even clash.

Coupled with this, the care delivery objectives could be holistically developed and entirely visible to the patient and their immediate carers. The goals of each element of care would be identified, and progress against these recorded. This would avoid the risk of one element encouraging a patient to think of being able to self-care, whilst a partner service might be seeking to persuade them to accept a move into residential care. By having a shared CareBook of delivery and related intent, all agencies could easily integrate into the common pattern – or instigate discussions if they felt it necessary to change the objectives.

Such an electronic diary could also provide the co-ordination for care delivery, particularly where domiciliary delivery is concerned, with its difficulty of physical monitoring. If the schedule of care delivery requirements to the individuals is re-visualised as a worker-specific schedule, it becomes much easier to arrange an alternative provider if the scheduled carer is unavailable. Instead of the client waiting for care which does not come, the virtual care community would reform with a new member. Conversely, if delivery fails because the client is absent or ill this would be reported in real time to the appropriate lead professional. A further benefit would be that temporary absences whether for holiday or for hospital admission could be entered by the patient, and the team's input appropriately adjusted.

5. Enabling Technology

Though the individual concepts have been previously identified [1, 2], technological achievement has been more difficult. Common electronic record and data standards are intended, but progress is slow. A further drawback has been the limitations of messaging as a means of electronic communication. Web services and secure transmission methods have advanced rapidly, as has the concept of "Software as a Service" [5]. Field research in the UK linking software engineering and healthcare requirements has demonstrated the feasibility of an integrational broker approach which seeks specified data items from heterogeneous but trusted data sources, with a combination of verification and authorisation [6-9]. Such technologies open up the feasibility of controlled but reliable real time reading of records such as the CareBook diary. Brokers are commonplace in commerce.

Latest software technologies do now have the capacity to realise the potential of information integration implied by this proposal, and the main remaining technical challenge is to bring them together within one architecture. The three key elements are

- Software Service Technologies, combined with a semantic framework drawing upon healthcare ontologies, to provide the vehicle for information exchange;
- Broker Technologies that incorporate fine-grained role-based access control; and
- Negotation Protocols and algorithms.

Much of this was demonstrated in the highly-successful IBHIS project (Integration Broker for Heterogeneous Information Sources) [6-9]. Additional elements, such as negotiation (for planning) and access control have subsequently been explored more deeply in PhD studies and through other vehicles, with development and publication in hand.

Coupled with this would be assessment and harnessing of proven modern technologies. The concept is for a web-based record, but focused on the dairy and planned care delivery – existing concepts such as HealthSpace are a summary of past history. However, it is vital to avoid creating a digital divide, especially as many patients are elderly. This multi-channel access will be needed, with the potential to interact with interactive television, existing health record systems, PDAs, and new generation mobile phones in particular.

6. The Challenges of Prototyping and Development

6.1 The Challenge of Tackling New Concepts and Visions

It is clear from this analysis that what is primarily required to move to truly patient-centric electronically supported care delivery is not fundamental software research nor new technology, but rather a change in mindsets within the health sector, and its complimentary partners such as social care, to re-conceptualise and then re-engineer their information management processes. This is as much as cultural change as a technological development, requiring as it does refocusing away from provider-orientated records to a truly patient-centric delivery schedule. The traditional role of the healthcare provider as the source of all wisdom, coupled with extreme pressures on resources, has hitherto reinforced provider-centric thinking, and the lack of interest in resource-scheduling and customer-focused information technologies.

Taking a detached view, other service sectors would consider the consumer-centric and resource-managing views as natural. The travel and leisure industries manage successfully to join together the components of a customised holiday so that the client receives an integrated booking combining road travel to the airport, flights, hotel with choice of catering style, and even individual booked leisure activities. The thought of boarding an aeroplane without knowing hotel availability until after arrival would be totally unacceptable, yet this is the health sector's approach when a health professional says to a patient that they require a range of other services providing in a coordinated manner but the commissioning professional has no information about availability, timing, or sequencing.

Some service industries are totally dependent upon multi-view coordinated scheduling. For instance in civil aviation the passenger has a client view comprising booking, check in time, seat allocation, and special catering. The operational service has a view of the individual plane's multiple journeys in one day, into which are interleaved appropriate staff allocation for each leg and the loading of meal trolleys for each journey. At the same time, the individual staff member has a duty roster view, and this is different according to the staff category such as pilot or cabin crew. Meanwhile, supportive services including engineering, ground handling, and financial management all have their view of the day's activities – both routine and special priority issues.

Civil aviation has the benefit of being a new industry with comparatively limited past history and tradition, and therefore it has been able to adopt rapidly new information

technologies. Similarly, manufacturing industry operates just-in-time approaches which link customer demand with component delivery and manufacturing and despatch, and has seen the need to invest in information systems and restructuring delivery to achieve this.

By contrast with aviation or manufacturing, health care for a sick or dependent person is much more ethically imperative and vital, and therefore healthcare should be striving to adopt such concepts rather then merely reinforce current concepts and mind-sets. It is understandable how approaches have remained rooted in paper-based concepts, and electronic systems have not been adopted while they could not meet the special and vital requirements of healthcare, and its concomitant requirement for reliability combined with flexibility. But those constraints have now been removed, and it is important to demonstrate to the healthcare sector and its patients the new opportunities.

6.2 Technical Developments as the Enabler

Not only is the healthcare sector, and its partners in social care, not used to electronic scheduling and negotiation or using electronic diaries, but until recently it was difficult to organise. Healthcare time management is challenging, and brokering between conflicting needs is a component part. Secure means of sharing data between non-secure locations has been difficult. However, recent advances in thinking and in software support change this. Complex scheduling can now be achieved with different views of the schedule, and there are rule-based systems for negotiation. Mobile communications and encryption open new possibilities. Hand-held devices are increasingly sophisticated, and high quality colour screens offer opportunity to present dates, time and other dimensions graphically.

The resultant challenge is to integrate both the technologies, and the thinking. This requires coordination of different software and hardware interests, concurrent with finding health partners willing to innovate though using not just fresh technology, but the concomitant fresh thinking.

6.3 Finding Agents of Funding and Prototyping

A further challenge is finding appropriate sponsoring funding agencies. The challenge is not primary research, but re-bundling of software services, software techniques, and hardware to provide the integrated platform. Research organisations see this as outside their scope as there is no fundamental research, commercial bodies are generally not ready to pick something up until it has been developed to working prototype stage, and health care organisations fear the disruption more than they are enthused by the potential benefit. Moreover, healthcare organisations are working under such strong resource pressures that diversion of operational funding into this type of new paradigm development cannot be seen ethically or in business terms as their top priority.

There is also the challenge of reengineering inter-organisational activities. Small scale developments would mean both old and new approaches running in parallel involving the same organisations and staff, and possibly the same patients, whilst large scale change involves a degree of disruption and short term efficiency risk which would need very careful management. The author, with clinical and computing academic colleagues, is in active discussion with potential pilot sites whilst concurrently looking for an appropriate funding source. However, it is clear that both healthcare systems and e-health technologies are much more structured and tuned to developing new technologies along existing approaches and mind sets than to finding radically new solutions with existing technologies re-packaged, with the undesirable effect of deepening silos and divisions rather than refocusing to put the patient, and efficiency of care delivery, foremost.

7. Conclusions

The combination of web services and broker technologies, linked to a further shift to true patient-centred health (and social care) services to citizens, is now achievable. Further benefits would be the setting of care packages feasible from the moment of commitment, and real time monitoring of service delivery to a pattern more closely integrated to the citizen's pattern of life. With this common view of the patient's needs coupled with sharing of care goals and the purpose of key interventions, the "virtual team" could truly come into existence. Opportunities are now arising, not least through European programmes, and it is important to exploit these.

The eChallenge in this respect is not to hanker continuously for new eTechnology in healthcare. Instead, the deeper eChallenge is to consider how other service industries have re-focussed their attitudes and processes to a truly consumer-centric one, harnessing new information management solutions (integrating hardware and software) to enable and achieve this. Other commentators have highlighted the inappropriate under-investment in the biomedical research arena in service delivery aspects as opposed to pure science, and the same is proving true in eHealth [9, 10]. Harnessing the technologies described here to enable optimal scheduling of resources, assurance of care delivery and the provision of truly patient-centric care, is just such an example of how major progress can be made with eHealth, if priorities can be framed to harness eHealth in a new way.

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