

# Development and evaluation of a memory clinic information system

Archana TAPURIA<sup>a,1</sup> and Matt EVANS<sup>b</sup> Tony AUSTIN<sup>c</sup> Nathan LEA<sup>a</sup>  
Dipak KALRA<sup>d</sup>

<sup>a</sup>Senior Research Fellow, CHIME, UCL

<sup>b</sup>Consultant in Psychiatry, Berkshire Healthcare NHS Foundation Trust

<sup>c</sup>Principal Research Associate, CHIME, UCL

<sup>d</sup>Clinical Professor in Health Informatics, CHIME, UCL

**Abstract:** Aim: To describe the requirements, development and evaluation of a cognitive disorders and older persons' clinical and research application, outlining the conceptual and practical challenges. **Methods:** A technology development methodology was used to develop a database of people being investigated for or diagnosed with cognitive disorders as well as their carers. The methodology involved phases of requirements gathering, modeling and prototype creation, and 'bench testing' the prototype with experts. **Results:** This case study suggests that construction and population of a memory clinic and research database is feasible, but initial development is complex. Its utility can be evaluated to some extent and was found to be acceptable to most users. **Discussion and Conclusions:** The development of a system needs to take in account existing data collection methods and other information systems used. The GreyMatters system can be considered a supplementary or complementary health record that sits alongside the main Trust information system. Integrating data from multiple systems enhances utility to clinical and research users.

**Keywords.** Mental health system, dementia, cognitive disorder, evaluation

## Introduction

Memory clinics have become the most common way for adults who develop cognitive problems to be assessed, diagnosed and treated. Good memory clinics are multidisciplinary and holistic, integrating health and social care as well as the voluntary sector (National Audit Office 2007) to meet the needs of patients and their relatives and carers [1]. Standards for memory clinics are specified in the United Kingdom by the Memory Services National Accreditation Programme [2].

At its conception, much time was spent prescribing dementia drugs and monitoring their use and it was necessary to demonstrate to the Primary Care Trust that prescribing protocols were adhered to. It was also recognized that valuable clinical data could be used for service development, research recruitment and primary research purposes. Recently, the importance of research has been a key component of the G8 Dementia Summit pledge to find a cure or disease modifying treatment by 2025 [3].

---

<sup>1</sup> Archana Tapuria.

Thus, there was a need for a system to be developed to aid the clinical and administrative processes of assessing, diagnosing, managing, prescribing and treating older adults with mental health problems and adults with cognitive disorders. The system was also to record consent for patients and their carers to participate in research to facilitate recruitment of patients in clinical trials. Restricted ‘researcher views’ and generation of data in fully anonymised form is beyond the scope of the initial stages of the system. This memory clinic system was named ‘Greymatters’.

### 1. Methods

The main steps in the process were documenting formal set of requirements, clinical modelling using archetypes, knowledge driven application, iterative design, deployment and end user satisfaction testing.

Requirements were gathered from clinicians, pharmacists, and administrative staff from Berkshire Healthcare Foundation Trust (BHFT). A team of two clinicians, and three technicians from CHIME worked closely with the clinician who represented BHFT as the client. Technical support was provided by the Information Department of BHFT in relation to testing and deployment. They were handled with the help of a Wiki shared between CHIME and BHFT. Each issue was recorded and discussed on the Wiki and the solutions were posted there.

The software requirements specifications followed the IEEE Standard [4], and an electronic health record standard EN 13606 [5][6] was used. Clinical modelling was done through archetypes [7][8] and the project complied with data protection and privacy legislation.

The main areas covered were: Demographics; GP details; Alerts/allergies; Consent including research consent; Research orientated diagnosis and clinical registers; Cognitive symptoms; Assessment scales; Older Persons Mental Health Liaison Service Referral Data; Medical summary; Medication. An example screen is shown below.

- ▼ C AssessmentScales 1
  - ▼ D Mini Mental State Examination
    - Test Location
    - Registration Score
    - Delayed Recall Score
    - Remarks
    - Informant
    - ScoreTotal
    - DenominatorScore
  - ▼ D Bristol Activities of Daily Living Scale
    - Test Location
    - Basic Activities of Daily Living Subtest Score
    - Orientation Subtest Score
    - Instrumental Activities of Daily Living Score
    - Remarks
    - Informant
    - ScoreTotal
  - ▼ D Montreal Cognitive Assessment
    - Test Location
    - NoncuedDelayedRecallScore
    - CategoryCuedDelayedRecallScore
    - Informant
    - ScoreTotal
    - DenominatorScore
  - ▼ D Demenz-Detektion
    - Test Location
    - <= 11yearsEducation
    - Registration# 1RawScore
    - Regiastration# 2RawScore
    - DelayedRecallRawScore
    - Informant
    - ScoreTotal
    - DenominatorScore
    - Remarks

## 2. Results

An evaluation was undertaken to assess user satisfaction and system usability of GreyMatters in 2013. The ASQ & CSUQ [9] were chosen as they have good internal consistency and allow assessment at overall system level as well as for individual system functions. The CSUQ provides 3 factors of analysis (System Usefulness, Information Quality, and Interface Quality) and an overall score. The ASQ asks for any given task 3 questions relating to satisfaction of: ease of use; time to complete task; and support information. Both the CSUQ and ASQ use a 7 point scale to record responses ranging from strongly agree (1) to strongly disagree (7) with positively expressed questions and a score of 4 representing the mid or neutral view.

A list of 16 past and present users of the system were emailed a copy of the CSUQ as well as a list of 7 scenarios that reflected real world use of the system. These ranged from searching for and registering a patient to entering clinic or research. They were asked to choose a minimum of 3 scenarios that reflected their normal use of the system and asked to complete the ASQ for each of the relevant scenarios.

There were a total of 10 responders (5 administrative staff, 3 clinicians and 2 research staff) who completed the CSUQ and a total of 29 ASQs covering 6 scenario areas. Results for the CSUQ and ASQ are presented in tables 1 and 2 respectively.

Averaged responses on the CSUQ (see table 1) for all user types show consistency across the 3 factors with overall score of 3.35. Breakdown of the staff groups suggest greater satisfaction from clinicians (overall score 2.32) than administrative staff (3.75). Analysis of individual user scores suggest polarised views in the clinician and administrative staff groups with responses ranging from 1-7 in both groups. Quality of supporting information was rated worst by the administrative group (4.06).

Responses on the ASQ (see table 2) show variation according to the task performed. Greater satisfaction was expressed for recording assessment scale data (2.25), recording a medication plan (2.60), recording research consent (2.79) and registering a patient (2.94). Dissatisfaction was expressed with recording a new drug (5.5) and entering liaison referral data (7.0). Clinicians and research staff were generally more satisfied than administrators. Analysis of individual responses again shows considerable polarity with responses ranging from 1-7.

Overall responses to the CSUQ and ASQ demonstrate mild to moderate satisfaction with the overall system and with individual tasks. Most notably recording of new drug and recording of liaison referral data were considered unsatisfactory although the low number of responders on these tasks (2 and 1 respectively) may reduce the validity of these results. It is apparent that certain individuals across the staff groups are strongly satisfied and others strongly dissatisfied with the same tasks and with the system overall.

It is possible that satisfaction scores are overall lower due to the extra complication of using this system in addition to the Trust's main electronic health record and also the need to maintain at least 3 other spread sheets to capture and manipulate required data. Further, limited resources have meant that written supporting information is scant and as yet updates to address known issues have not been possible. The results however support that the first version of the system is an acceptable tool for clinical, administrative, business and research use and forms a useful part of the wider information architecture.

**Table 1: CSUQ results**

	All	Admin	Clinical	Research
OVERALL (1-19)	3.35	3.75	2.32	3.34
SYSUSE (1-8)	3.35	3.74	2.25	3.42
INFOQUAL (9-15)	3.37	4.06	2.14	2.98
INTERQUAL (16-18)	3.33	3.23	3.00	3.78

**Table 2: ASQ Results**

All users n=10 Ave (range)	Over-all ASQ	Admin users n=5 Ave (range)	Admin ASQ	Research users n=2 Ave (range)	Research ASQ	Clinician users n=3 Ave (range)	Clinician ASQ	
	2.94		3.17		2.50			register a patient (n=5)
3 (1-6)		3.25 (1-6)		2.5 (2-3)				overall satisfied
2.67 (1-5)		2.75 (1-5)		2.5 (2-3)				satisfied with time
3.17 (1-7)		3.5 (1-7)		2.5 (2-3)				satisfied with support info
	2.79		3.78		1.83		2.44	record research consent (n=8)
2.63 (1-5)		3.33 (2-5)		2 (2-2)		2.33 (1-5)		overall satisfied
2.38 (1-4)		3.33 (3-4)		1.5 (1-2)		2 (1-3)		satisfied with time
3.38 (1-7)		4.67 (3-7)		2 (2-2)		3 (1-6)		satisfied with support info
	2.25		3.33		1.33		1.00	record assessment scale data (n=8)
2.25 (1-7)		3.25 (1-7)		1.5 (1-2)		1 (1-1)		overall satisfied
2.25 (1-7)		3.5 (1-7)		1 (1-1)		1 (1-1)		satisfied with time
2.25 (1-7)		3.25 (1-7)		1.5 (1-2)		1 (1-1)		satisfied with support info
	5.50		4.67				6.33	record new drug (n=2)
5 (4-6)		4 (4-4)				6 (6-6)		overall satisfied
5.5 (4-7)		4 (4-4)				7 (7-7)		satisfied with time
6 (6-6)		6 (6-6)				6 (6-6)		satisfied with support info
								record diagnosis (n=0)
-	-	-	-	-	-	-	-	-
	7.00		7.00					complete liaison referral (n=1)
7 (7-7)		7 (7-7)						overall satisfied
7 (7-7)		7 (7-7)						satisfied with time
7 (7-7)		7 (7-7)						satisfied with support info
	2.60		2.50				2.67	record medication plan (n=5)
2.6 (1-6)		2.5 (1-4)				2.67 (1-6)		overall satisfied
2.6 (1-6)		2.5 (1-4)				2.67 (1-6)		satisfied with time
2.6 (1-6)		2.5 (1-4)				2.67 (1-6)		satisfied with support info

### 3. Discussion

A challenge in modern healthcare is the constantly shifting requirements for information recording to meet stakeholder needs. GreyMatters has found a niche within the ecosystem of IT systems in the Trust. Its strength is that it provides flexibility to record clinical information that the other Trust systems can't. It can therefore be considered a supplementary or complementary health record that sits alongside the main Trust system. The use of multiple systems is not always ideal and presents a real challenge to time pressured staff. This and the lack of documentation and on screen help are reflected in the variability of user scores in the evaluation. Overall the assessment of the system in an early stage, suggests it is an acceptable solution.

The benefits of the system have been further enhanced by developing data flows between the different systems. For instance, new patient registrations within the main Trust system are automatically imported into GreyMatters. Data from GreyMatters and the other Trust systems are combined to produce textual and graphical reports which are delivered to individual users on a nightly basis. Data is automatically imported into the spreadsheets used by clinics to manage clinic workflow. A browser based data mining tool has been developed to enable proposed research feasibility testing as well as a recruitment tool for identification of research participants.

### 4. Conclusion

The well established standards on which the GreyMatters architecture is based provide the Trust with confidence that the system can meet the medico legal challenges of an electronic health record. The system has been deemed acceptable by most users although there is dissatisfaction with some aspects by some users and needs further work. Additional value has been added by listening carefully to how clinical, administrative and research staff work and by pushing data and reports to them automatically in a format they want.

### References

- [1] Improving services and support for people with dementia. Report by the Comptroller and Auditor General. HC 604 Session 2006-2007, 4 July 2007; National Audit Office.
- [2] Memory Services National Accreditation Programme, Standards for Memory Services, Third Edition June 2012, Pub. No. CCQI131 Royal College of Psychiatrists.
- [3] <http://dementiachallenge.dh.gov.uk/2013/12/12/g8-dementia-summit-agreements>.
- [4] IEEE Standards. 830-1998 - IEEE Recommended Practice for Software Requirements Specifications.
- [5] Kalra D. Requirements for an Electronic Health Record Architecture. ISO18308:2010.
- [6] Kalra D, Lloyd D. EN 13606 Electronic Health Record Communication Part 1: Reference Model. CEN TC/251, Brussels. February 2007.
- [7] Ingram D, Beale T, Heard S, Kalra D. The openEHR Foundation. Accessed Jan 2012. Available at: <http://www.openehr.org>.
- [8] Tapuria A, Kalra D, Kobayashi S. Contribution of Clinical Archetypes, and the Challenges, towards Achieving Semantic Interoperability for EHRs. *Health Inform Res* 2013; 19(4), 286 - 292.
- [9] IBM Computer Usability Satisfaction Questionnaires: Psychometric Evaluation and Instructions for Use. Lewis JR. *International Journal of Human-Computer Interaction* 1995; v.7 n.1 p.57-78 2007.