Towards designing Health IT that works
– Lessons from 25 years of HCI/CSCW research

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A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas

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Abstract. CSCW as a field has been concerned since its early days with healthcare, studying how healthcare work is collaboratively and practically achieved and designing systems to support that work. Reviewing literature from the CSCW Journal and related conferences where CSCW work is published, we reflect on the contributions that have emerged from this work. The analysis illustrates a rich range of concepts and findings towards understanding the work of healthcare but the work on the larger policy level is lacking. We argue that this presents a number of challenges for CSCW research moving forward: in having a greater impact on larger-scale health IT projects; broadening the scope of settings and perspectives that are studied; and reflecting on the relevance of the traditional methods in this field - namely workplace studies - to meet these challenges.
**CSCW & HCI [Socio-technical]**

Computer Supported Cooperative Work
(& Human Computer Interaction)

- **Focus:**
  - Understanding the nature of collaborative work
  - Designing systems to support that work

- **Methods:**
  - Ethnographic/qualitative studies for purposes of design
    - Unit of analysis – workplace, work practices
    - Rich descriptive accounts of work
  - User-centred/participatory design process
  - Building & deploying systems to meet needs/create possibilities
  - Studying systems in use
### Table 1. Distribution of core CSCW-related papers by venue and year (including cumulative totals).

<table>
<thead>
<tr>
<th>Year</th>
<th>JCSCW</th>
<th>ECSCW</th>
<th>CSCW</th>
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**Review Corpus – 145 papers in total**

Thematic review of 128 core + 17 papers from related venues [from 1st CSCW conf 1986]
Summary of CSCW/HCI Insights

Workplace study insights ‘from the ward floor’ showing rich and diverse ways

situated practical work of care is achieved

(complex, contingent, collaborative; role of coordinative artefacts eg PRs, whiteboards, paper;

... requiring in-the-moment in-context processing of information & negotiating complex interdependencies)

impact of new IT on this work

(transforming, evolving, hindering?)

ongoing work ‘to put technology to work’ in context

(co-adaptation, socio-technical)

[Images thanks to Ina Wagner, Charlotte Tang]
Why does this matter?


Utopia/Dystopia by Dylan Glynn
‘Maturing’ Electronic Health Record Initiatives

From small scale – pilots & localised initiatives:
   1967 Dr Lawrence Weed - PROMIS project

To large scale national agendas – huge investments!

- Austria:
  - Elga etc

- Australia:
  - 2001 National eHealth Project -> HealthConnect AUD$1 billion

- Canada:
  - 2001 Canada Health Infoway 2001 CAD$2.1 billion

- Denmark:
  - Connected Digital Health program

- UK:
  - 2002 National Programme for IT -> Connecting for Health £12-14 billion

- US:
  - Nationwide Health Information Network; recent US$20 billion to digitize health system
E-health system a $1bn ‘scandal’

Joanna Heath

Health Minister Peter Dutton has launched an inquiry into the former Labor government’s e-health records system, after what he described as a poor take-up by doctors and patients.

“The problem is that the former system was managed and owned by another company,” Mr Dutton told a press conference yesterday.

Mr Dutton said the review into e-health records would be chaired by Richard Royle, executive director of the UnitingCare Health group in Queensland.

Mr Royle would be assisted by psychologists and other front-line health workers to guarantee all Medicare Locals will remain open and their jobs are secure.”
Australia's 'struggling' e-health records under review

Summary: The Australian government has announced an inquiry into the rollout of the AU$1 billion e-health record system implemented under the former government.

By Josh Taylor | November 3, 2013 -- 22:13 GMT (14:13 PST)

“Very little interest from the public and doctors in signing up”

Only 5,000 shared health summary docs uploaded in total since 2011
“…my thinking was that people in the health system were at least as capable as those in the finance system.

If eftpos could link billions of bank accounts and financial institutions around the world, it should surely be possible for every Australian patient’s file to be copied, indexed, stored and securely made available to the patient and authorised treating professionals via the internet.

In retrospect, I had underestimated the difficulty …”

(prev Health Minister/Opposition Leader; recently elected Prime Minister)
Abandoned NHS IT system has cost £10bn so far

Bill for abortive plan, described as 'the biggest IT failure ever seen', was originally estimated to be £6.4bn

Rajeev Syal
The Guardian, Wednesday 18 September 2013

An abandoned NHS patient record system has so far cost the taxpayer nearly £10bn, with the final bill for what would have been the world's largest civilian computer system likely to be several hundreds of millions of pounds higher, according to a highly critical report from parliament's public spending watchdog.

The public accounts committee found that new regional IT systems for the NHS are
£7bn NHS electronic records 'achieving little' for patients

By Nick Triggle
Health correspondent, BBC News
18 May 2011

Patients are getting "precious little" from the NHS electronic care records system in England, a watchdog says.

The £7bn system to replace paper files is falling further behind schedule and in places where it has been introduced it is not working as it should.

The National Audit Office also said some patients would not even get one as large

"falling further behind schedule and in places where it has been introduced it is not working as it should."

[National Audit Office Report. 2011. (7bn, part of 11.4bn NHS IT project)]

Just 1 in 4 patients had records uploaded and records used just 167 times [2008 report on Pilot Projects]

“SCR spectacularly failed to deliver a raft of promised benefits to patients and doctors” [2010 comment from a Gov Minister to PULSE]
Politicians’ promises in 2002 – EPRs for all by 2005!
– set at Downing Street meeting 18 Feb 2002

- Patient by 2004/5:
  - receive telecare at home
  - access my own electronic records
  - know that a summary of my health record will be available
  - book appointments convenient for me (and get reminders)

- Doctor, by 2004/5:
  - EPRs will enable clinical data online & results reporting
  - prescribe drugs using computer support
  - save 30 mins/day chasing results & getting ready for ward rounds.
  - use patient summaries from EPRs eg for emergency care
  - know that clinical terms in use are clearly defined and support analyses in practice

“Successful introduction … depended on interaction between multiple stakeholders from different worlds (clinical, political, technical, commercial) with different values, priorities, and ways of working …

Benefits … seem more subtle and contingent than … anticipated, and clinicians may not access them.

Complex interdependencies, inherent tensions, and high implementation workload should be expected when they are introduced on a national scale.“

[BMJ - Greenhalgh et al 2010]

Socio-technical reasons!
### 2002 LSP specification 607 pages - Training p585

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Required response</th>
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<tbody>
<tr>
<td><strong>940.1 Overview</strong></td>
<td>Effective training will be critical to the successful implementation of ICRS, eBooking and other services, and usage of any service within the health community. LSPs will be expected to work closely with the Authority and with relevant NASPs to provide training as needed. The initial outcome of this process shall be the preparation of a training plan by LSPs for discussion during the project initiation phase. Each bidder shall describe its overall approach to the provision of training to support implementation of LSP Services, including local implementations of ICRS and eBooking.</td>
</tr>
<tr>
<td><strong>940.2 Identification of Training Needs</strong></td>
<td>Bidders shall undertake an analysis of training needs by specified user type and identify the most appropriate method of training delivery for each user group. Each bidder shall indicate how the training needs of user would be assessed.</td>
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<td><strong>940.2.1</strong></td>
<td>The main clinical staff groups requiring access to the LSP Service shall include:</td>
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<td>• consultants and other senior doctors;</td>
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<td>• junior doctors;</td>
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<td>• GPs;</td>
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<td>• nurses (hospital and community);</td>
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<td>• social workers;</td>
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<td>• pharmacists, pathologists and radiologists;</td>
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<td>• Allied Health Professionals (AHPs);</td>
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<td>• paramedics; and</td>
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<td>• NHS Direct and out of hours staff.</td>
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<td>These clinical care staff will benefit from the integration of local patient-centred information to support the operational delivery of care. They will also have an interest in the common data held on the Spine and will require training on the access routes to both local and nationally-available data.</td>
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‘Blaming the user in Medical Informatics’

[Forsythe 1992]
### 2002 LSP specification 607 pages - Change Management p595

<table>
<thead>
<tr>
<th>Business Process Change</th>
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| **960.2** | **Bidders shall work with the Authority to review, and where appropriate, re-design business processes and procedures to ensure maximum benefit is gained from the implementation of the LSP Services.**  
  
  **Each bidder shall indicate its approach to undertaking process re-engineering exercises.**  
  
  **960.2.1** | **Bidders shall undertake a health community-wide review of existing processes as part of preparation for implementation. Processes and procedures will vary across the Trusts and healthcare sites within a health community, and a flexible approach will therefore be required. The review of current processes will seek to establish where improvements can be made in each of the following areas:**  
  
  - quality of process;  
  - time to undertake process;  
  - steps within the process;  
  - staff resources required;  
  - cost reduction; and  
  - mitigation of current risk.  
  
  **Each bidder shall describe the approach it would propose to reviewing existing processes.**  
  
  **960.2.2** | **Bidders shall work closely with local modernisation teams engaged in current business process reviews.**  
  
  **Each bidder shall describe how it would propose to achieve effective joint working.**  
  
  **960.2.3** | **Bidders shall ensure that any proposed changes to business or clinical processes are fully consulted upon to secure staff acceptance of the usability of the solution.**  
  
  **Each bidder shall describe how it would achieve this.**

**Quotes from Bossen 2011, Greenhalgh et al 2009**

'View from nowhere'

'Codifiable, transferrable, enduring'
In sum... (too) many Health IT systems aren’t working

- Problems with
  - Top-down vision, unrealistic targets
  - Delivery of systems that
    - don’t ‘fit’, don’t work, don’t deliver benefit
    - don’t recognise the ‘work to put the systems to work’

- Increasing recognition of socio-technical
  - Issues not so much technical as organisational, social, cultural, professional, managerial ...
  - Importance of the sociotechnical
    - 2011 IOM ‘Health IT and Patient Safety’
    - 2013 IJMI Special Issue In Press ‘A sociotechnical perspective of health information technology’
A CSCW/HCI [S-T] view on ‘process’

Healthcare work in-situ & health IT
Repeating themes & issues

- **Diverse ensemble** of people & resources co-opted in ‘doing’ of care
  - Formal & informal documents, paper & technology, space, time, mobility, artefacts eg whiteboards
  - Communication, coordination, information flows, collaborative sensemaking

- **‘Tacit, context bound and ephemeral’** knowledge & practices
  - People often not aware of strategies, skills, processes, ensembles of resources/people etc they co-opt; taken for granted practices

- **Tensions** between
  - local practices, individual differences & standardised systems approach;
  - primary and secondary users of EPR data; different professional groups; etc

- **Problems of systems design, deployment**
  - High costs of ‘unintended’ consequences, extra work, work-arounds
  - ‘user’ participation does not = good solutions
  - Benefits not given … requires ongoing co-adaptation
Understanding healthcare as collaborative work

[Note: Some illustrative examples only, with random ref examples and mainly around EPRs, to give a feel for types of issues explored in CSCW research.]
Move to electronic patient records

[Images: Fitzpatrick; I Wagner]
How paper also has value
How paper supports right-time right-place conversations

[Note the embedded conversations around two drug orders]
How records are written and read

- Uses of free text
  - Order of entries (temporal overview), structure & ‘geography’ of entries

- Reading what is there and what isn’t there

- Indicating provisionality, thought processes, conditions excluded, etc [Hardstone et al 2004] ... collaborative sensemaking
How records enable multiple perspectives

- Enabling multiple perspectives
  - Eg ‘dossier representif’ [Schneider & Wagner 1993];

- Ensemble of ‘working sheets’ alongside ‘formal record’ [eg Chen 2010; Fitzpatrick 2004; Osterlund 2007; Wilson et al 2006]

- Value of some forms of redundancy for work practice/coordination [eg Cabitza et al 2005]
Changes to documentation with electronic records

Move to more structured data entry – codes

- Doctors, nurses do not think in codes
- Increased interaction work to navigate, choose

- Delayed entry of provision discussions/diagnoses until jointly agree/final [eg Hardstone et al 2004]
- Changes to recording psycho-social information [Zhou et al 2010]
- Bad redundancy [eg Bossen 2011]
- etc…
Roles of physicality, mobility, space, arrangements: awareness, coordination, communication...

Making work visible in very particular ways
[Images: Fitzpatrick]

Fig 8: Whiteboard and control desk in surgical suite [Scupelli et al 2010]

Fig 2: Wallboard op schedule.
[Bardram 2000]
How temporal ‘asynchronous’ coordination happens

Coordination & communication flows
“Production and negotiation of temporal work orders” [Reddy et al 2006]

- Work orders within shifts
- Shift changes/handoffs [eg Wilson et al 2006; Tang & Carpendale various; Zhou et al 2010]
- Patient handovers [eg Randell et al 2006, Munkvold & Ellingsen 2007, Bjorn & Hertzum 2011]
- Assembly, disassembly of info [eg Tang & Carpendale 2007]
- Planning and scheduling [eg Wagner, Bardram various]

[Images thanks to Charlotte Tang]
Changes to collaboration, sharing, getting overviews…

[eg Tang & Carpendale (various); Randell, Wilson various etc]
Challenges of working with Mobile EPRs – COWs

Tang and Carpendale 2008

Images thanks to Charlotte Tang
Creating workflows … & workarounds

- Clinical processes

- Disparity between formal models encoded in records, clinical guidelines/pathways etc & situated clinical practice [eg Bossen 2006, Cabitza et al various, Chen 2010, Zhou 2009]

- Experiences:
  - Extra work to ‘workaround’
    - Parallel documentation systems
  - Shifts in power, status
    - Certain practices more visible and other types of invisible
Global standardisation vs local practices

Tensions between (how to balance?):

   large scale integration & standardisation  
     – accountability, uniformity, scalability …

& specificity of local work practices  
   – control, responsiveness, tailorability …

“Important discrepancies between the presumptions of the role of the [EPR] in achieving service integration and the ways in which the medical workers actually use and communicate patient information” [Hartswood et al 2003. p. 241 – emphasis added].

Management’s quest for full-scale integration contrasted with each laboratory’s need for tailored laboratory systems [Ellingsen & Monteiro 2006]

Became a device for social control and surveillance as it enforced particular standardized procedures upon practice and took away the nurses’ professional discretion [Bjorn and Balka 2007]
**Case: standards & EPRs at work**

- **Experiences:** Fragmentation, lack of overview, difficulty placing/finding info, bad redundancy, extra time needed

- **Flip-over effect:** model of work becomes model *for* work
  
  "BEHR stands out as an individualistic, disembodied, and decontextualised abstraction, a view from nowhere" [p489]
And much much more …

- **About**
  - Particular units eg radiology, ER, OR, ICU etc
  - Multi-disciplinary team meetings & use of video conferencing/digital resources; Telemedicine
  - Telecare, home care, self care; Community care; GP settings
  - From micro (eg micro-coordinative practices during surgery) to macro (eg Infrastructures)

- **Recent emergence of**
  - Longer term engagements in the field
    - Following pre-post deployment, change/adoption
  - ‘meta’ reviews/reflections & conceptual development
    - Drawing concepts/frameworks across multi-site or diverse related studies (10 papers to date)
Designing Systems to support collaborative work

Implications from studies taken in different directions
   For practice
   For policies
   For design ***
**Systems ‘at home’ - for self care / chronic care**

**Examples of disruptive innovations empowering patients?**

[Beth Mynatt, WISH 2011]

- eg Mahi for diabetes mgmt  
  [Mamykina et al 2008]
- eg eDiary – Diabetic pregnant women  
  [Aarhus et al, 2009]
- & many more … enabled by mobile technologies
Systems in hospitals
[limited work; focus mostly on specific artefacts/functions]

Fig 1: Preoperative communication and coordination system (PoCCCS) in OR suite

Eg: Electronic scheduling/planning

Fig 2: PoCCS in ward, recovery, and sterile depts.

[Bardram & Hansen 2010]
CSCW Report card?
Workplace study insights ‘from the ward floor’ showing rich and diverse ways

the situated practical work of care is achieved

(complex, contingent, collaborative; role of coordinative artefacts eg PRs, whiteboards, paper;

… requiring in-the-moment in-context processing of information & negotiating complex interdependencies)

impact of new IT on this work

(transforming, evolving, hindering?)

ongoing work ‘to put technology to work’ in context

(co-adaptation, socio-technical)

[Images thanks to Ina Wagner, Charlotte Tang]
Different conceptualisations of [electronic] patient records

As data / archive
Accountability device

designing records …
information focus …

As facilitating care
Coordination device

designing practice …
practice focus …
Corpus characteristics point to gaps/challenges

- **Countries**: biased to US, parts of Europe
  - Nth America (42; US 31); Europe (74; Denmark 27)

- **Settings**: hospital dominates
  - Hospital (97), GP (7), home/community (21)

- **People focus**: limited non-med/nursing; vendors, mgrs, etc & patients!
  - Team (61), nurses (27), doctors (17), therapists (1), family (3), patient (20)

- **Contributions**: how do these relate to national-scale initiatives?
  - Focus on individual workplaces
    - How do they scale? Impact at local level?
  - Mostly implications for design (but few systems)
  - Few follow ongoing adoption process

Impact/Value ... especially at the ‘global’ level?
Moving forward
- Challenges to increase scale, complexity, impact

Utopia/Dystopia by Dylan Glynn
‘Global’/national initiatives underestimating the difficulty of Health IT

- Differing agendas, foci of interest, & ways of seeing, acting, measuring:
  - **Stakeholders**: political/economic, commercial, management, professional groups/disciplinary perspectives, etc
  - **Approaches**: accountability’ [top down] & ‘work practice’ [bottom up]

- Assumptions that aren’t working
  - Knowability, codifiability, countability, controllability generalisability
  - Technology & benefits as ‘given’ - utopian (dystopian) solution

- Evaluations just in terms of ‘outcomes’
  - Not recognising impacts on work & importance of ongoing adoption & co-adaptation in putting technology to work in local contexts

Moral imperative to contribute to making IT work
Moving CSCW to a middle-out approach?

[adapting/re-interpreting Coiera 2009’s three national e-health approaches]

Top-Down
Engaging with accountability, organisational, change agendas, infrastructure

*CSCW sensitivities & principles as ‘routine’ consideration*

Middle-Out
Balancing top-down (global) & bottom-up (local) concerns

*CSCW engagement with ongoing co-evolution of socio-technical systems that work – resources for acting*

Bottom-Up
Strategic participatory *in-situ* studies, broadening concerns,
*Drawing out implications for all levels/stakeholders*
How to engage across all levels?

- Need teams with **mix of professions, stakeholders, concerns**
  - Who will these be? How to work together?
  - Who will fund this?

- Need to **engage with vendors, procurers, policy makers etc** as equally legitimate foci of study
  - Study their practices, needs etc
  - Negotiate tensions between ‘ward floor’ and other levels?
  - Pull out broader implications from studies for all stakeholders?

- Need to better **identify and ‘package’ common themes**
  - Multi-site; cross-studies analyses; higher order practices, insights
  - Making lessons more accessible, helping to create new assumptions about work and IT
How to better include people to design systems that work?

“valuable input is not necessarily guaranteed by users as professionals, but from knowledge produced from a stance within practice”

[Bossen 2011]

- How to do better user participation and co-design?
  - Seek input at all stages, not just initial design
  - Include more professional/stakeholder voices/perspectives
  - Focus on situated practices rather than tech in isolation
  - *** Focus on resources for action, not models for action

- *** How to train reflective practitioners – all stakeholders?
  - Making tacit explicit, critical self-awareness, able to better engage in design input and ongoing co-adaptation

- How to integrate needs of both primary (clinical care) and secondary (accountability) users effectively?
How to evolve methods to engage in ‘middle out’?

Hybrid methods? New methods? Cross-disciplinary tensions?

- **Understanding:**
  - Need to move from just an analytical/descriptive stance:
    - To engage with scale and ‘larger’ change processes?
    - Taking more of an action research stance?

- **Designing:**
  - Smaller scale cycles and/or agile methods?
  - Focus on designing ‘work’ not just technology

- **Evaluating:**
  - Not reifying technology or assuming ‘fixed state’ – interpretation of outcomes from specific context?
  - Unpacking social/contextual processes in putting tech to work; lessons for interpretation/use for different contexts
Thank you

Discussion?

Post talk addition:
Ideas from audience discussion for how to do ‘middle out’:
- Commit to create study reports for different audiences as a matter of course eg to clinicians, to administrators etc [Rebecca Randall]
- Create strategic [ideally funded] partnerships with relevant community/advocacy groups [Tiffany Veinot]
- [I’m sure there were others that I’ve forgotten…]

Any other thoughts?