Sowerby Symposium
Understanding ‘real life’
patient benefits in taking part
in dementia research

Hilary Doxford
September 2016

Join Dementia Research Champion
Alzheimer’s Society Research Network Volunteer
Today

• My background

• My involvement

• My frustrations

• The benefits
Who am I?

• Work experience
• Volunteer (primarily for the AS)
• Diagnosis
Some of my difficulties today

• My brain is slowing down
• Declining short term memory – barn fire
• Minimal ‘working’ memory 1234 x 5678
• Background noise – hate it
• Learning – I can’t
• See things incorrectly – brain jumps to worst case scenario/potential threats
• Following stories/TV plots – mission impossible!
Cont.

• Superstores, locating products/meal planning
• Lateral thinking/cryptic thinking
• Social situations, no conversation topics
• Sense of smell - cannot name the source
• Comprehension – missing jigsaw pieces
• Stopped dreaming (or can’t recall them)
• Losing my way on routes I should know
• Mix up my words/typing /writing errors
• Emotions – harder to control
Initial thoughts
Three words

• Fear

• Despair

• Hope ....but from where?
Fear

• You look ahead

• You have a survival instinct

  – Pain

  – Fear itself
Despair

• What research

• No signposting

• Research hindrances

• The saddest days
Time our Enemy
Hope

• Year 1 not a lot

• Taking control

• Involvement
What is involvement?
Long-recognized importance of participation

The research lifecycle

- Engagement
- Participation
- Involvement
- Design & planning
- Delivery
- Analysis & reporting
- Dissemination & implementation
- Evaluation & impact
- Commissioning & funding
- Topic identification & prioritization

Policy

- Regulation
Research involvement

• RADAR Bristol
• Neuro-inflammation and amyloid Hammersmith
• ALF Exeter
• IDEAL Exeter
• MADE Kings London
• Hippocampal changes Bristol
• EOAD genetics Exeter/Bristol
Every voice (woof) counts
Frustrations

• Anecdotal evidence
• Public attitudes/silent majority
• Success criteria
• Implementation and dissemination
• Silos
• Inability to diagnose, perceived failures
Data  Knowledge  Information
My dilemma and my changing perceptions

• Initially
  – Take/do anything
• Then
  – Take some ownership of my destiny
• Today
  – Risk/benefit decisions
In a nutshell

• I love being involved in research, it is therapeutic
• I am listened to, maybe improving the research
• I am well looked after, I receive better care
• I have interesting discussions
• I gain an insight into the latest theories and results
• I have a purpose and a value
• Crucially it keeps my brain active
• I have a better understanding of my disease progression
• and just maybe I will be one of the lucky ones who is part of the trial that finds the cure
Those three words

Today have changed

• Fear has reduced to concern

• Despair is now personal happiness

• Hope is now great hope
Leading to

For a better quality of life for longer
My philosophy

• God grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference.

• Living one day at a time; Enjoying one moment at a time; Accepting hardships as the pathway to peace; ....

Reinhold Niebuhr
Thank you for listening and for all that you do from all three of us
Electronic health records are essential to high quality patient care

- EHRs can give patients more control over their own care
- Can reduce patient safety risk and improve diagnostics and care
- Can improve communication
- Can lead to better care for patients with chronic diseases
- Can optimise care

-2014 Sowerby Commission Report
Paperless 2020: All care records will be digital, real-time, and interoperable.
An online survey of doctors’ use of EHRs in England

AIMS AND OBJECTIVES

To describe implementation of key UK policies by conducting an online survey of doctors from across England use and perceptions of EHRs

500 DOCTORS SURVEYED IN ENGLAND

150 GPs
Partner
Salaried GP

350 SC
Consultant
Associate
specialist
Staff Grade
SPR Years 4+
More GPs use electronic functionalities than secondary care doctors

- Communicating with other clinicians outside their organisation: 79% (GP) vs. 76% (SC)
- Entering patients' notes: 53% (GP) vs. 98% (SC)
- Accessing clinical data about a patient who has been seen by a different organisation: 46% (GP) vs. 77% (SC)
- Sending prescriptions to pharmacies: 39% (GP) vs. 83% (SC)
- Sending or receiving order requests from other organisations: 35% (GP) vs. 74% (SC)
- Communicating electronically with patients to support remote consultations: 31% (GP) vs. 33% (SC)
Secondary care doctors still receive important patient medical information through the post.

- GP Records: 44% (Post), 18% (Electronically/Email)
- Current Prescriptions: 33% (Post), 38% (Electronically/Email)
- Records of prior admissions to your hospital: 77.00% (Post)
- Records of prior admissions to other hospitals: 34.00% (Post), 15% (Electronically/Email)
Extent to which doctors believe that EHRs could affect the ease of sharing medical records between primary and secondary care organisations.
Electronic access to clinical data when a patient has been seen by a different provider: is it available, and would doctors use it?

Access to clinical data: Is it available?

<table>
<thead>
<tr>
<th>Availability</th>
<th>SC</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is available</td>
<td>49</td>
<td>85</td>
</tr>
<tr>
<td>It is not available</td>
<td>50</td>
<td>15</td>
</tr>
</tbody>
</table>

If it is not available, would you use it?

<table>
<thead>
<tr>
<th>Availability</th>
<th>SC</th>
<th>GP</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would use it</td>
<td>90%</td>
<td>93%</td>
</tr>
<tr>
<td>I would not use it</td>
<td>10%</td>
<td>7%</td>
</tr>
</tbody>
</table>
Clinical activities doctors would like to complete electronically

- Discharge summaries after hospitalisation: 80% (GPs) vs 75% (Secondary care)
- Care handover letters from outpatients: 78% (GPs) vs 73% (Secondary care)
- Hospital prescriptions: 76% (GPs) vs 81% (Secondary care)
- Uploading documents: 63% (GPs) vs 72% (Secondary care)
Doctors’ views towards patient access to EHRs

Patients’ rights to access EHR in 2015 and 2016 (% agreement)

- **GP**
  - There is a clearly defined process by which patients can access their electronic health records held by my organisation: 64% in 2015, 80% in 2016
  - Patients have access to their electronic health record held within my organisation: 46% in 2015, 74% in 2016
  - Patient access to electronic health records would increase my workload: 75% in 2015, 73% in 2016
  - The benefits to patients from accessing their electronic health record outweighs the risks: 25% in 2015, 28% in 2016

- **SC**
  - There is a clearly defined process by which patients can access their electronic health records held by my organisation: 47% in 2015, 50% in 2016
  - Patients have access to their electronic health record held within my organisation: 20% in 2015, 24% in 2016
  - Patient access to electronic health records would increase my workload: 51% in 2015, 52% in 2016
  - The benefits to patients from accessing their electronic health record outweighs the risks: 37% in 2015, 39% in 2016
Conclusions

• 1) GPs are engaging with EHRs, though there is more work to be done in secondary care

• 2) GPs and secondary care doctors agree that EHRs will help information flow by reducing information lost due to fragmentation

• 3) Concerns arise when patients are brought into medical data sharing approaches, particularly around working patterns, how to handle data, and how to interact with patients
Patient held records break down the barriers between care settings.

North West London’s Care Information Exchange allows the sharing of medical records with patients and providers, and communication.

Economic evaluation illustrates the potential benefits of implementing this programme.
What is Self Care?
Care Information Exchange

The ability to view, add and share information about patient care.

The opportunity for patients to take more control of their own health and care.

New ways of communicating with health and social care professionals.
How much is it costing us?

- Digital health information tools cost money and require investment.
- Cash savings might not be seen immediately.
- Policy makers need support in making these investment decisions.
Cost Benefit Analysis

Costs
- Implementation
- Design
- Build
- Test
- Startup costs
- Running costs
- Equipment
- Training
- Recurrent costs

Benefits
- Reduced face-to-face GP consultations
- Reduced GP telephone consultations

Wider benefits
- Reduced hospital inpatient admissions
- Reduced A&E admissions

Outcomes
- Savings in number of GP appointments
- Savings in number of GP telephone consultations
- Enhanced shared decision making
- Reduced referral time
- Improved medical adherence
- Improved patient safety through increased error reporting
Results

• Over 6000 GP face to face consultations saved in the first year.

• Over 4000 telephone consultations saved in the first year.

• Almost £310,000 saved within the first year.

• Savings will increase as more patients enroll onto the programme.
Conclusion

• Economic evaluations are possible, but CCGs are under-resourced to collect good quality data.

• CCGs need the analytical support to collect and interpret relevant, reliable, and up-to-date data.

• Patient access to online medical records has the potential to create savings locally as well as enhance patient engagement.
A new home care model for people living with dementia

Dr Des Holden, Medical Director, KSS AHSN
14 September 2016
The future workforce of the NHS

Age in the NHS

AGE BREAKDOWN OF ENGLAND'S WORKING POPULATION¹
- 12% - Under 25
- 23% - 25 to 34
- 24% - 35 to 44
- 23% - 45 to 54
- 16% - 55 to 64
- 4% - 65 and over

AGE BREAKDOWN OF THE NHS WORKFORCE²
- Under 25 - 6%
- 25 to 34 - 22%
- 35 to 44 - 25%
- 45 to 54 - 29%
- 55 to 64 - 16%
- 65 and over - 2%
Patient demographics

The Lancet 2012 380, 37-43DOI: (10.1016/S0140-6736(12)60240-2)
Population vs workforce

Source: Office National Statistics National Population Projections

No. School leavers age
No. 60 and over
The problem

We need a different model of care

One that relies less on face to face contact and reduces admissions to secondary care
Work programme of Kent Surrey and Sussex AHSN

• Quality and safety improvement* (provider CEO led improvement board) – collects data from all providers on process metrics associated with improved outcome and uses collaboratives to drive improvement through learning.

• National patient safety collaborative

• Living well for longer*

• Innovation and industry* (surgeries, NHS test bed board, acute provider CEO led)

• System leadership* (local STP enabling and national through AHSN Network)

• Future workforce*

• *Living labs
Living Lab

- Primarily a space and a philosophy

- Secondarily a place
Living Lab

• A safe space where the right people seek to address wicked problems through new insights

• Centred on the need of citizens (which includes all of us) rather than the needs of the system

• Involves citizens experiencing health and care problems and citizens caring for and about them and a variety of expert by training or experience.

• Encourages new collaborations to maximise chance of new solutions

• Draws on established experience (southern Denmark) and perceived local strengths (e.g. 5G connectivity UoS)
My Life with Technology - A Trusted User Lab in Odense Municipality

A Living Lab Case

During the last 10 months, Odense Municipality has, in collaboration with Public Intelligence, tested assistive technologies in the private homes of 15 families. The families all face different challenges due to various disabilities, and they all share a wish of becoming more self-reliant – and this is exactly where technology matters. Each family has chosen assistive technologies they believed could help and support the specific needs of their families.

A Living Lab of Trusted Users

The living lab involves 15 families, 3 family coordinators, and 5 consultants from the municipality. The families have been selected by the municipality to for the purpose of representing a broad range of families who would typically be referred to assistive technology. Some families had an interest in technologies, some did not – this difference in interest was important in order to see if it had any influence on the families' approach and the success of the tested technologies.

The professionals from the municipality were trained in the test methodology and was introduced to a lot of different technologies.

The role of the family coordinators has been to support the families during their technology choice; encouraging them to try new technologies and afterwards supporting them implementing them in their homes. Moreover, the family coordinators have been identifying barriers and evaluating the effect on the families. A big part of the family coordinators’ role was their approach: they had to put their professional expertise aside and let the families chose for themselves.

Activities in My Life with Technology

The project consists of three main cycles, as illustrated below. In each cycle, the families can chose as many technologies as they find relevant, and test them in a following 3 month period. Some families chose 1-2 technologies each time, some 10-15. Interestingly, all families give it a lot of thought before choosing technologies they expect to have an effect.

Before the first cycle, each family was subject to an ethnographic study identifying needs, desires and challenges. These insights were used in order to select the technologies for the whole process, but also as a baseline for future evaluations.

In each cycle, new technologies have been selected according to the users' wishes and unmet needs. After the test periods, the effects of the selected technologies have been evaluated, and if they each had an effect, the families could keep the technologies for the full project period.

<table>
<thead>
<tr>
<th>Date</th>
<th>Cycle 1</th>
<th>Cycle 2</th>
<th>Cycle 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>November 2015</td>
<td>SPRINT 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technology choice 1</td>
<td>The families chose freely among all assistive technologies from the municipality's own assistive technology depot</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identification of needs</td>
<td>The families describes wishes for other technologies and needs where they do not know of any existing technologies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>April 2016</td>
<td>SPRINT 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technology choice 2</td>
<td>A technology expert selects new technologies according to the families' wishes and needs. Again the families can choose freely among all the technologies.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identification of needs</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>September 2016</td>
<td>SPRINT 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technology choice 3</td>
<td>A technology expert selects new technologies according to the families' wishes and needs. Again, the families can choose freely among all the technologies.</td>
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Results so far:

- The citizens do not chose a lot of technology, but are very selective in their choices. And their choices are focused on how they can enhance their self-reliance.
- The citizens feel heard and seen and thereby get a better collaboration with the municipality.
- The citizens take more control over their situation.
- It is easier to implement technologies citizens have selected themselves.
Innovate UK bid

Using technology to improve the quality of life for people living with dementia
Solution

Monitoring patients remotely
Partners

Kent Surrey Sussex Academic Health Science Network

Surrey and Borders Partnership NHS Foundation Trust

University of Surrey

Alzheimer's Society

Public Intelligence

Health technology providers

NHS Clinical Commissioning Groups

Royal Holloway University of London
Technology Partners

Nine companies with 25+ devices and services, including monitors, sensors, apps, hubs, virtual assistants, location devices and wearables
Thank you
Des Holden

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