Putting patients in control of their records

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I am not just a patient ........

I am a mother, sister, partner, friend, learner, educator, humanist, carer, supporter, cook, designer ...

(after A. C. Grayling, 2006)
We are not just “families”………..

We are nurses, engineers, judges, cleaners, waste disposal operatives, rocket scientists, brain surgeons, care workers car salespeople, children, comedians, cooks….

(after Brindle after A. C. Grayling, 2014)
Our health – our lifetime’s work!

Our most important project

Most of it done

“Home Alone!”
"You are already your own doctor."
Tom Ferguson, M.D., 1985

Our interactions with the healthcare system are only the tip of the iceberg.

Self-care is and has always been our predominant form of health care.

We are welcoming new patients. Please click here to join us now!

NEW: See patient survey and what patients think of the service we offer at the practice
Tell us what you think about the new look home page
URGENT: Learn about care.data and whether you and your family wish to opt out of sharing your data with 3rd parties without your consent

Welcome to our new Home Page which has been compacted to provide you with the most essential information for most of your needs as a patient in the practice.

The main website offers a great deal more information for those who wish to learn more about what they can do for themselves supported by a large number of resources we have gathered to support you and your family's needs.

If you or your loved ones would like to sign up for FREE online services then please click here.

You can send secure non-urgent messages online by logging into EMIS Access once you have registered or send an email about non-medical matters to htmcpatient@nhs.net
Test results

- All test results available
- Blood tests
- If regularly tested, can monitor trends
- Understandable, value, graphic, Normal / Abnormal
- Labtests Online
- Comment by doctor
- Can avoid repeating tests
- No need to contact practice
Summary of significant events

- Form filling, insurance & benefits etc.
- Useful when you are asked the same thing over and over again!
- Good to be reminded of progress
- Links to trusted sites where information is available
Letters, referrals etc

- All communications that go in & out of the practice
- Gives the patient confidence, knows what has been done
- No need to contact practice
- Letters from consultants......supposed to send but often don’t
- Can check understanding and roles in what happens next
- Can use the letters to inform others who don’t communicate
- Examples.....France, Grandson, Yvonne, Margaret
Mobile Phone app

• Have information available anywhere home and abroad with just 2 passwords! How cool is that?
• A large percentage of the population have a suitable mobile phone
• Information about passwords can be stored under ICE
• Access information can be put on the lockscreen
• If someone steals the phone, passwords can be changed
Consultations etc.

- Patient retention of information can be as low as 10%
- Can check understanding & what happens next
- Can get family or friends / carers help
- Language difficulties ......Australia.........Nursing homes
- Safe medicine
- No need to contact practice
What is needed is for all the patient information to be ‘joined up’

- GP records
- My information (blood pressure, glucose levels, etc.)
- In-patient information
- Out-patient information
- Information from other agencies (social care, physiotherapy, chiropody)
- Information from carers
- And so on
Health Pledge
Small Steps lead to Big Changes

www.healthpledge.co.uk

Will you support us?
Almost every successful person begins with two beliefs: the future can be better than the present, and I have the power to make it so.
The 6 Ps for Success

• Patients and the Public
• Partnership of Trust
• Paradigm Shift in Healthcare
• Practice makes Perfect
Patients with access to their GP electronic health records at Haughton Thornley Medical Centres 23rd April 2015

Total **4167** patients

Total **1826** males; **2341** females; **35%** of total patient population-11731 patients
<table>
<thead>
<tr>
<th>Type of patient</th>
<th>How many have signed up</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>752/1760</td>
<td>42%</td>
</tr>
<tr>
<td>COPD</td>
<td>113/350</td>
<td>32%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>336/806</td>
<td>41%</td>
</tr>
<tr>
<td>Cancer</td>
<td>109/279</td>
<td>38%</td>
</tr>
<tr>
<td>Depression / Anxiety</td>
<td>887/1448</td>
<td>61%</td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
<td>36/76</td>
<td>47%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>170/464</td>
<td>36%</td>
</tr>
<tr>
<td>Low back pain</td>
<td>1161/2585</td>
<td>44%</td>
</tr>
<tr>
<td>URTI</td>
<td>2425/6350</td>
<td>38%</td>
</tr>
<tr>
<td>Admitted during December 2014</td>
<td>11/25</td>
<td>44%</td>
</tr>
<tr>
<td>Learning disability</td>
<td>8/46</td>
<td>17%</td>
</tr>
<tr>
<td>Bengali patients</td>
<td>535/1499</td>
<td>35%</td>
</tr>
<tr>
<td>Medications ordered online</td>
<td>896/11731</td>
<td>7%</td>
</tr>
<tr>
<td>Total patients</td>
<td>4167/11731</td>
<td>35%</td>
</tr>
</tbody>
</table>

For latest data: see http://www.htmc.co.uk/pages/pv.asp?p=htmc0328
The flying, empowered patient

Patient  Engage / Create Interest  Enable  Inform  Activate  Reactivate  Build momentum  Flying Empowered Patient  Safety Netting
Key principles

• The patient is (almost) always right
• Get stuff done
• Consent is king
• Cut corners at your peril
• Workflow, workflow, workflow
• Let’s make it fun
• The devil lies in the detail
• Don’t stop now
DREAM BUILDERS

"THE WAY TO GET STARTED IS TO QUIT TALKING AND BEGIN DOING."

-Walt Disney
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You can send secure non-urgent messages online via EMIS Access or send an email about non-medical matters to htmcpatient@nhs.net.
Do you want to see what your doctor or nurse has written about you or check your GP Electronic Health Record

Well done. You are a couple of steps away from getting access and understanding of your GP electronic health records. Watch this short video which tells you what to do next.

STEP 1
Register your PIN NUMBERS
(You will need to collect this from the receptionist)

STEP 2
Complete ONLINE QUESTIONNAIRE
to get access to the GP electronic health records

Learn more about online services here  Click here to download free Patient Access app for your iPhone/Android

Please make www.htmc.co.uk your favourite website for all health related matters. Send an email to htnpatient@nhs.net if you have any problems.

Please look at some of the links provided below which provide information on what records access and understanding means:

<table>
<thead>
<tr>
<th>What does Records Access and understanding mean?</th>
<th>About Records Access</th>
<th>Background and information on Records Access including YouTube videos</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the benefits and challenges of Records Access</td>
<td>An Example Health Record</td>
<td>Keeping your Information Safe</td>
</tr>
<tr>
<td>Maintaining confidentiality</td>
<td>Frequently Asked Questions</td>
<td>How many patients have got access to their records at Haughton Thornley Medical Centres</td>
</tr>
</tbody>
</table>
1. Default Section

1. What is your name, post-code and e-mail address
   Name: 
   Postal Code: 
   Mobile phone number: 
   Email Address: 
   Home phone Number: 

2. I am doing this questionnaire for myself?
   ● Yes
   ● No
   If you answered NO then please state your name and relationship to the patient
   
3. Can you read and understand English?
   ● Yes
   ● No

4. Have you registered for ordering repeat prescriptions and booking appointments on-line?
   ● Yes
   ● No
5. Are you happy to use passwords to access your record?
- Yes
- No
- Other (please specify)

6. After you have been to the doctor or to the hospital, you can check if the encounter has been recorded and what was discussed. Do you agree this is a good reason to have access to your records?
- Yes
- No
- Other (please specify)

7. Would you like to feedback what you think of the Records Access system?
- Yes
- No

If yes then please inform the Patient Participation Group, Practice Staff, Practice Manager or send an email to htmcpatient@nhs.net or write in the box below


8. There maybe an instance when accessing your medical records online, you may read some information that could be shocking or upsetting. What do you do if this happens and you cannot speak to your doctor / nurse immediately?

- Not view the test results but wait until you see the doctor / nurse
- Panic and get worked up
- Look at some of the recommended websites under self care on www.htmc.co.uk
- Wait and contact the practice the next working day
- Contact 111 to get further information
- Contact GoToDoc, the Out of Hours service (details available at www.htmc.co.uk)
- Go to A&E for further help

Other (please specify)

9. You see a new letter has arrived in your electronic health record. You open up the letter to find it is about another patient in the practice. What do you do?

- Read it then tell others what the person suffers with
- Inform the practice
- Stay quiet and not tell anybody about it

Other (please specify)
10. Would it upset you if you read something somebody else has said about you with regards to your health?

☐ No
☐ Yes - I don't want this information kept in my record
☐ Yes - You should not believe what others say
☐ Yes - This could destroy our relationship
☐ Don't know

Other (please specify)

11. Do you feel you understand what Records Access means?

☐ Yes
☐ No

Other (please specify)

Feel free to write any comments especially if you say No to the evaluation part of this questionnaire. If you would like any information regarding this questionnaire contact the practice directly or via e-mail (htmcpatient@nhs.net)
Challenges

• Who has the Time?
• Whose Benefit?
• Who does What?
• Who Pays for it?
• Who Needs it or just Wants it?
• Could it open risk of Litigation?
• Could it widen Inequalities & highlight Prejudices?
So why do it?

Because it is **MORALLY** the **RIGHT** thing to do
How askmyGP works as a system
How can we help you?
Patient enters problem, can choose named GP

First name *
Brian

Surname *
Freeze

Date of birth *
17
4
1955
c.g 1st January 1965 would be 01 01 1965

Gender *
Male

I'd like help with *
- A medical problem
- Repeat prescription
- My results from a test
- Any other question

I'd like help from *
- Anyone at the practice
- First available GP
- A named GP
- A nurse

Please state the problem or question *
I have a chest infection

A medical problem is confidential to you and your GP

Ask my GP
Condition identified from entry. Add contact details, to be checked.

Please select from the following:

- [x] Chest infection
- [ ] None of the above

I am the

- [ ] Patient
- [ ] Parent
- [ ] Carer

How would you prefer us to contact you? *

- [ ] Email
- [x] Text to mobile
- [ ] Phone call

Contact phone *

07999 123456

Contact email *

brian.freeze24@coldmail.com

Continue
Easy questions come one at a time. Branched logic ensures relevance.

As part of your current illness, have you measured your temperature when you had a fever?

Do you have a runny nose?

Do you have a stuffy nose, head congestion, or blocked nose?

Do you have swollen glands in your neck?
The patient reviews the history & sends. GP can now make fully informed decision.

- Complaint: I have a chest infection
- I'd like help with: A medical problem
- I'd like help from: A named GP
- I am the: Patient
- Contact Phone: 07999 123456
- Contact Email: brian.freeze24@coldmail.com

**Chief Complaint**
Brian Freeze is a 59 year old male. The "chest infection", and "chest infection" screening questionnaires were administered. The following are his responses.

**History of Present Illness**

#1. "chest infection", "chest infection"

Associated Signs and Symptoms
He reported: Recent respiratory symptoms improved then worsened.

**Review of Systems**

Constitutional
He reported: Feeling feverish. Did not measure temperature when feverish.

Ear, Nose, and Throat
He reported: Swollen glands in neck. Runny nose 5 to 6 days. Thin discharge from nose.

Musculoskeletal
He reported: Muscle pain.

**Risk Factors, Prevention, and Patient Issues**

Patient Issues
He reported: Needing excuse from work.

**Skipped Questions**
Do you have excessive mucus dripping down the back of your throat or do you find yourself continually clearing the back of your throat?
Do you have a sore throat?
Do you have a cough?
Managers Provide the Context for Patients and Clinicians to excel

• Why inside a practice?
  – Unit of healthcare
  – Culture starts here
  – Whose work is it
  – Issues relate to all 3 groups of people
  – Shared purpose / values
  – Critical mass for change
Managers Provide the Context for Patients and Clinicians to excel

• Why outside a practice?
  – Sustainable change requires interdependency
  – Funding linked to behaviour change and outcomes
  – Commission for better outcomes
  – Practitioners can support patients / carers too
  – Networks and systems, not organisations
  – Social Media
Take home messages

• Listen to patients and staff
• We all want & need access to records and understanding
• Patients will co-produce records with clinicians
• Increasingly patients will share record with those who need it
• Build a system / culture to support patients, public & staff
• Getting explicit informed consent is easy
• This is not FREE but there are SAVINGS to be had
• We have gained massive experience and knowledge on how to do this
• The time is NOW to get started
• www.htmc.co.uk shows the way
• Engage on @IngridBrindle & @amirhannan
That's been one of my mantras — focus and simplicity. Simple can be harder than complex. You have to work hard to get your thinking clean to make it simple. But it's worth it in the end because once you get there, you can move mountains.