

Auditing your own health record – how, what, why?

useMYdata.org

Queens Hotel, Leeds

22 November 2018



Background

Govt response to Caldicott (2016)

The brief we're working to

'By December 2018, individuals will be able to access a digital system to understand who has accessed their summary care record'.

And

By March 2020, people will be able to use online services to see how their personal confidential data collected by NHS Digital has been used for purposes other than their direct care.

Government response to the National Data Guardian for Health and Care's (Caldicott) *Review of Data Security, Consent and Opt-Outs* (2016), published as "Your Data: Better Security, Better Choice, Better Care" (July, 2017):

The standard we're working to

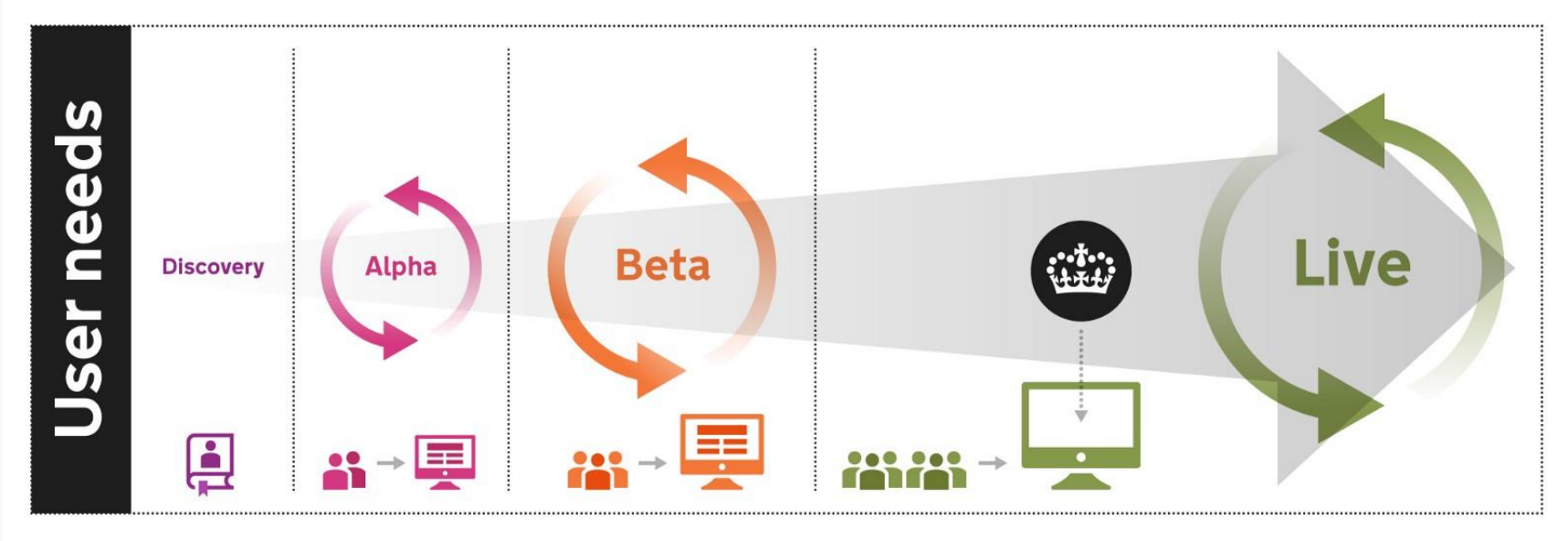


Digital Service Standard

- 1 Understand user needs. Research to develop a deep knowledge of who the service users are and what that means for the design of the service.
- 2 Put a plan in place for ongoing user research and usability testing to continuously seek feedback from users to improve the service.
- 3 Put in place a sustainable multidisciplinary team that can design, build and operate the service, led by a suitably skilled and senior service manager with decision-making responsibility.
- 4 Build the service using the agile, iterative and user-centred methods set out in the manual.
- 5 Build a service that can be iterated and improved on a frequent basis and make sure that you have the capacity, resources and technical flexibility to do so.
- 6 Evaluate what tools and systems will be used to build, host, operate and measure the service, and how to procure them.
- 7 Evaluate what user data and information the digital service will be providing or storing, and address the security level, legal responsibilities, privacy issues and risks associated with the service (consulting with experts where appropriate).
- 8 Make all new source code open and reusable, and publish it under appropriate licences (or provide a convincing explanation as to why this cannot be done for specific subsets of the source code).
- 9 Use open standards and common government platforms where available.
- 10 Be able to test the end-to-end service in an environment identical to that of the live version, including on all common browsers and devices, and using dummy accounts and a representative sample of users.
- 11 Make a plan for the event of the digital service being taken temporarily offline.
- 12 Create a service that is simple and intuitive enough that users succeed first time.
- 13 Build a service consistent with the user experience of the rest of GOV.UK including using the design patterns and style guide.
- 14 Encourage all users to use the digital service (with assisted digital support if required), alongside an appropriate plan to phase out non-digital channels/services.
- 15 Use tools for analysis that collect performance data. Use this data to analyse the success of the service and to translate this into features and tasks for the next phase of development.
- 16 Identify performance indicators for the service, including the 4 mandatory key performance indicators (KPIs) defined in the manual. Establish a benchmark for each metric and make a plan to enable improvements.
- 17 Report performance data on the Performance Platform.
- 18 Test the service from beginning to end with the minister responsible for it.

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How we develop a service



How Discovery altered our brief

Audit and Transparency Foundation Service

The brief we're now working to

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And

How might we better educate the public about their health records and how they are organised? And how can we do that in a way that inspires confidence in the NHS's management of their health records and the data they contain?

The flow

Step 1: Search for records

Find out where your health records have been looked at

Use this service to see where your Summary Care Record has been looked at.

Before you start

You need an NHS login to use this service. If you do not have an NHS login you'll be able to set one up.

Start now

Step 2: Login check

Do you have an NHS login?

Yes

No, I'll need to create one

or

I'm unsure

Continue

Step 3: Record selection

You have more than one health record

One of your health records is called a Summary Care Record.

Continue

Step 4: Record details

Your Summary Care Record comes from your GP record

It tells health and care staff:

- your allergies
- your medicines
- any reactions you've had to medicines

Continue

Step 5: Staff access

Health and care staff can look at your Summary Care Record:

- in an emergency
- at a walk-in centre
- at a pharmacy

The only time they will not ask you if they can look at your Summary Care Record is when it's an emergency.

Continue

Step 6: Locations

We keep track of when your Summary Care Record is looked at

Continue

Step 7: Summary

In the last year Your Summary Care Record was looked at 6 times

In 3 different care settings

3 times in an NHS trust	2 times in a Care home
1 time in a Pharmacy	

See where your health records have been looked at

Step 8: Recent views

September 2018

Friday, 21 September

3:32pm
Leeds Teaching Hospitals NHS Trust

Saturday, 15 September 2018

8:32pm
River view care home

Thursday, 13 September 2018

11:24am
Leeds Community Healthcare NHS Trust

March 2018

Tuesday, 13 March 2018

11:24am
Leeds Community Healthcare NHS Trust

View more

Footer

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ECOUTER Study

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In collaboration with Prof Madeleine Murtagh and Dr Mwenza Blell

Video about ECOUTER:

<https://research.ncl.ac.uk/d2k/ourresearch/ecouter/>

For publications, search for “ecouter minion murtagh” in Google Scholar

Summary Care Record Survey

<https://nhs-digital.citizenspace.com/live-services/patient-scr-ai-survey/>



#datasaveslives

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Please get in touch!

Today's question

What would world class NHS data transparency look like?

World Café / Ecoutter



Countdown

<https://youtu.be/cGc6-Od28Pg>

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