Talking to patients and the public about their health and care data

Resources for health and care staff and partners to talk about patient and citizen data and its use for Population Health Management

May 2023

Version No. 01

Created by SmartCo in collaboration with Yorkshire & Humber Care Record

Commissioned by Louise Sinclair, Yorkshire & Humber Care Record



Instructions for staff





We created this document to:

- help you talk to patients and the public about their data
- explain 'population health management'
- help patients and the public to understand how and what their data is used for in Yorkshire & Humber.

Go through the slides with the individual, allowing them to see the content.

You can find further resources for staff at the end of this document.

You can use the **scale** below to guage a person's level of understanding as you go through the resource. It pops up on certain pages and should help you to know whether to explain something in more detail or use some of the external resources -

This resource has been co-developed and tested with over 100 people across Yorkshire & Humber. But there's always room for improvement. Please send any feedback to: hnf-tr.yhcr@nhs.net

These **buttons** take you to additional external resources such as videos or webpages. Use these if people want to access further information

> It takes approximately 5 minutes to use this resource

Flick through the pages of the resource with the arrows

I do not understand

I completely understand

The Yorkshire & Humber Care Record





Let's begin!

The Yorkshire & Humber Care Record







The Yorkshire and Humber Care Record (YHCR) is a digital shared care record that allows patient information from different sources, to be viewed securely and updated in real time.

No data is stored on the YHCR itself, it is stored in GP and Hospital records, for example, to ensure **your data is always safe.**



Your health and care data







Health and care staff can view this for your care

The YHCR allows

personal health data and

de-personalised health

data to be viewed by

different people.

The use of de-personalised health data for research and planning is called population health management.



research and

planning

What is population health management?





Population health management is the use of people's <u>de-personalised health data</u> to understand the health and care needs across a population and tailor services to meet those needs.

This helps to **improve health** and **prevent illness** through **research and planning**.

It involves the **NHS** and other public services including **social services**, **schools**, **housing associations** and **councils**.



1 3 4 5

De-personalised health and care data





De-personalised data

does not identify an individual, because identifiable data has been scrambled or removed.

X It does not include

- name
- full address
- full date of birth

✓ It does include

- diagnoses
- hospital admissions
- ethnicity
- postcode region

The data is de-personalised and although you are not 100% anonymous, it would be extremely difficult for anyone to be identified.







Anonymous

Less identifiable

More identifiable



Viewing de-personalised health and care data





Public services (e.g. local authorities, housing associations, branches of national government and social services) can view de-personalised data and combine it with other sources of data to plan public services to improve health and wellbeing.

More information & resources

Local authorities

1:18

Who can and cannot access health data
63 views • 7 months ago

Click on the circles to see specific examples.

Joined up data to reduce asthma

Joined up support in care homes

Joined up data to reduce obesity

Example: joined up data to reduce asthma







Population
health data shows
a large amount of
asthma cases in
an area



Information from the local authority shows that the council houses are cold and damp



Information from
the government
shows that the area
also has poor air
quality

Outcome:

The local authority agree to **insulate** all the council houses, and also to start a "**no idling**" campaign to encourage motorists to turn off their engines to improve air quality, resulting in a reduction of asthma cases.





Example: joined up support in care homes







Care home staff notice a resident is becoming more forgetful, they visit the GP



Test results from the **GP** and **memory assessment service** are accessed by a specialist



Population
health data supports
the specialist to
make a diagnosis
of dementia

Outcome:

Through connecting the dots between services and using population health data around dementia, the resident receives a quick diagnosis and the medication and support they need.





Example: joined up data to reduce obesity







The council has a new budget for providing free exercise classes where needed



Population
health data shows
obesity amongst
workers on a
business park



Information from the **business park** shows workers want to exercise but don't have time

Outcome:

The council are working with the business park to set up **free exercise classes** that can be accessed during work time, resulting in a reduction in obesity and happier workers.





The importance of de-personalised data





Using data makes it possible to diagnose health conditions earlier and provide new drugs and treatments.

Data also helps the NHS plan for the future by understanding which services will be most needed to support health and wellbeing.



If you are healthy, you may not feel your data is of use. However, it's just as important to understand about healthy people in order to improve the health of others.



1 2 3 4 5

Data security and GDPR





Health and care providers holding your data are committed to protecting your data. Click on the links below to read about how your data is protected.

Cyber security
Information governance
Clinical safety



Your choice







You are **automatically opted in** to sharing your **de-personalised data** for the purposes of **population health management**.

You have the option of opting out, click here to find out more.



1 2 3 4 5





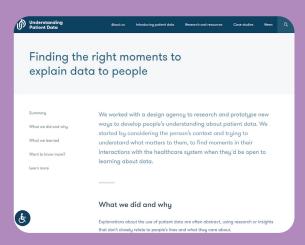
The end!



Other resources for health and care staff







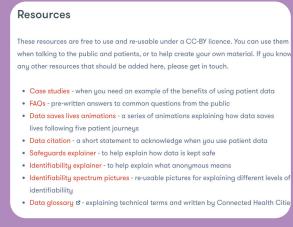
Webpage: Finding the right moments to explain data to people



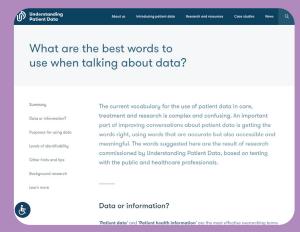
PDF: Quick guide to explaining how patient data is used



Video: Why do we need to talk about patient data?



Webpage: Further resources



Webpage: What are the best words to use when talking about data?

<u>Understanding patient data</u> has some excellent resources for staff. Click on the boxes to take you there.

Thank you.

This resource has been co-developed and tested with people across Yorkshire & Humber.

We hope you found it useful.

Feel free to provide feedback on this document or any other aspect of shared care records or population health management by emailing: hnf-tr.yhcr@nhs.net

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