



Frequently Asked Questions (FAQs) for Patients: Information Sharing

**North West London** 

Whole Systems Integrated Care (WSIC) Dashboard

The purpose of this FAQ is to answer questions regarding information sharing across North West London to support Whole Systems Integrated Care (WSIC) Dashboard.

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### Contents

1. What is the WSIC Dashboard?
2. Who is involved?
3. Why is it important and how is it different?
4. How will it benefit me?
5. What information is collected?5
6. What information isn't collected?5
7. Can I access my information?5
8. Can I request my information is updated if I think it is incorrect?
9. What happens if I don't want to share my information?6
10. Who can see my information?6
11. Who will not be able to see my information?
12. How do I know that my information will not fall into the wrong hands? What safeguards are in place?
13. Who's responsible for keeping my information safe?
14. How long is my information stored for?7
15. Is my information used in any other way apart from for my individual care?7
16. Will my information be sold to the private sector?
17. Can I ask for my information to only be used for my individual care and not for other purposes?9
18. How are patients involved in this programme?9
19. How are patients informed about this programme?9
20. Can I get any information in another language?10
21. What Can I do if I am not happy or have a concern about how my data is being processed?



North West London

## 1. What is the WSIC Dashboard?

The WSIC Dashboard is an electronic record used by health and care professionals use to record key information about your care. It's different from previous records as all the health and social care teams involved in your care can share a summary of relevant information from your health and social care records, providing a joined-up history of your care.

The health and care professionals that can use it include:

- GPs
- Hospitals, for example, accident and emergency, inpatient and outpatient
- Social care services
- Community care services
- Mental health services

Your WSIC Dashboard holds your contact details, your date of birth and your NHS number, as well as details about your health and treatment.

#### 2. Who is involved?

The WSIC Dashboard has been established by health and social care provider (e.g. GPs, hospitals, mental health and community providers, and social services) from across North West London.

For the purposes of the Data Protection Act, these partners collectively form the North West London Collaboration Partners and are the data controllers for WSIC.

Data is shared lawfully based on public interest (Article 6(1)(e) of the General Data Protection Regulation (GDPR)) and for medical purposes (Article 9(2)(h) of GDPR), and research purposes (Article 9(2)(j)). Your healthcare providers also have a duty under the Health and Social Care (Safety and Quality) Act 2015 to share data with all those involved in delivering your care.

More information on the North West London Collaboration Partners, who they are and what they do can be found at the following links on their website:

- The Partners: <a href="http://integration.healthiernorthwestlondon.nhs.uk/about-us/our-partners">http://integration.healthiernorthwestlondon.nhs.uk/about-us/our-partners</a>
- The Programme: <u>http://integration.healthiernorthwestlondon.nhs.uk/about-us</u>
- Governance: <a href="http://integration.healthiernorthwestlondon.nhs.uk/informatics">http://integration.healthiernorthwestlondon.nhs.uk/informatics</a>
- Contact Details: <u>http://integration.healthiernorthwestlondon.nhs.uk/contact</u>

You can contact our Data Protection Officer at NWLCCGs.wsic.dashboards@nhs.net or via our<u>postal address</u>. Please mark your correspondence with 'Data Protection Officer'.



You can find more information about the role of the DPO here.

#### 3. Why is it important and how is it different?

Previously, individual paper and electronic records were held by each of the different care services you use. For example, your GP, hospital doctors and district nurses would all have their own records. This meant they weren't able to see each other's information.

The WSIC Dashboard is important because it lets health and care professionals access information from other organisations wherever they are, making the treatment you receive safer and more accurate.

#### 4. How will it benefit me?

The health and care teams involved in your care will have access to better information which will enable them to provide you with more joined-up care.

Medication history, diagnosis, alerts and allergies are among key information shared among all your care organisations and means that:

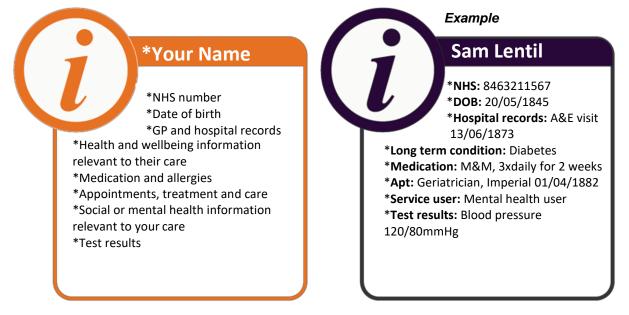
- you won't have to explain your medical history over and over again to different people
- you won't need to repeat details about your medications, treatments or medical history every time you see a new health or care professional; and
- you can be more involved in decisions about your care to support your health and well-being.

<u>Click here, to hear our patient stories and to find out more about why integrated care is</u> so important to people and their families.



### 5. What information is collected?

The information collected includes your name, address, postcode, your date of birth and your NHS number, as well as details of your health and treatment.



If you don't want to have an WSIC Dashboard created for you, you will need to let your GP know.

#### 6. What information isn't collected?

We won't collect information about a number of sensitive areas, including information about:

- abortion
- gender reassignment
- IVF
- sexually transmitted infections (STIs)
- abuse
- imprisonments and convictions
- complaints

This type of sensitive information is called coded information. For a full list of coded information, please see <u>Codes and Sensitive Codes (Version 2, 11th July 2016)</u>.

### 7. Can I access my information?

You have the right to access information we hold about you. You can do this at any time by contacting us through our contact page:

http://integration.healthiernorthwestlondon.nhs.uk/contact



#### 8. Can I request my information is updated if I think it is incorrect?

If you believe any of your information is inaccurate then you have the right to request it is updated. You may also request access to your information is restricted until the correction is made. Please use the contact page to get in touch:

http://integration.healthiernorthwestlondon.nhs.uk/contact

#### 9. What happens if I don't want to share my information?

It's your choice to share your information through the WSIC Dashboard. If you don't want to share your information, you can opt-out. Opt-out forms are available at your GP practice or online at:

http://integration.healthiernorthwestlondon.nhs.uk/informatics/information\_sharing

If you can't find a form in your GP reception, please ask the receptionist or your GP. Your GP will record your choice and your information will not be shared.

Opting-out won't affect your care in anyway. You'll still be able to receive health services. However, you will not receive the benefits of having an WSIC Dashboard.

Opting out could mean that:

- You will need to tell each professional providing your care about your medical history, treatment, allergies and medication.
- Decisions about your care may take longer
- Appointments and tests may be repeated.

If you change your mind and want your information shared you can inform the GP practice or care professional treating you, and they will mark your record.

#### 10. Who can see my information?

Your WSIC Dashboard will be seen only by health and care professionals directly involved in your care. This includes GPs, consultants, nurses and care co-ordinators.

#### 11. Who will not be able to see my information?

Only people who are directly involved in your care will be able to see your record. Anyone who is not directly involved in your care won't have access to your record.

# 12. How do I know that my information will not fall into the wrong hands? What safeguards are in place?

We have a number of security measures in place to protect your information from being accessed by the wrong people. This includes:

- All information collected about you being protected by the Data Protection Act 2018 (see Q.10 below)
- Controls are in place to restrict access to patient data. These are

#### Version 4 | May 2018



based on a professional's role. This means, they can only access the information they need to know. This is called Role Based Access.

- Annual review to check we are handling your personal information in line with national NHS provided security standards (provided by <u>NHS</u> <u>Digital</u>)
- We hold a Digital Governance Group which monitors how your information is used and who can access it. Three patient representatives sit on this board and their role is to support the patient's best interests
- We will only share your information with health and care organisations that have signed up to our legally-binding data use agreement. This includes safeguards to protect your confidentiality.

### 13. Who's responsible for keeping my information safe?

All NHS organisations are governed by the <u>Data Protection Act 2018</u>. By law they're responsible for your information and must keep it safe.

Under the Data Protection Act you have a right to have factually incorrect information changed or removed. If the information isn't incorrect, but you disagree with what has been recorded, you have a right to have your disagreement with the entry added to the record. If you're concerned about an inaccurate record, you should discuss this with the health or care provider responsible for the inaccurate entry.

### 14. How long is my information stored for?

Your data will be kept as per The <u>Records Management Code of Practice for Health and</u> <u>Social Care 2016</u>, which sets out what people working with or in NHS organisations in England need to do to manage records correctly. It's based on current legal requirements and professional best practice. Appendix 3 of the Code contains the <u>detailed retention schedules</u> and sets out how long records should be retained, either due to their ongoing administrative value or as a result of statutory requirement.

In this case as the integrated care record is made up of many components therefore the longest retention period applies and they are kept until 10 years after death.

# 15. Is my information used in any other way apart from for my individual care?

Researchers, doctors and people running health services use small amounts of information which doesn't directly identify you to understand how our health is changing and the best ways to plan services, monitor safety and evaluate NHS policy. This information is called 'de-personalised data'. They **won't be able to identify you** from this information.

De-personalised data is information about your care. It doesn't include

- name
- date of birth

Version 4 | May 2018





- phone number
- email
  address
- address
- NHS Number

You can find out more about de-personalised data at https://understandingpatientdata.org.uk

#### Improving health and care services

De-personalised data will be shared with Clinical Commissioning Groups (CCGs) to help them understand what types of services the NHS should provide and where. This will help them to commission better health and care services for you.

#### Research

The information from patient records is valuable to help understand more about disease and develop new treatments. The NHS may collaborate with academic researchers and industry partners to do this. To find out more about research work in North West London please see https://imperialcollegehealthpartners.com/what-we-do/services-forindustry/sme-surgeries/discover/



#### 16. Will my information be sold to the private sector?

# Your information will not be shared or sold for commercial purposes e.g. to banks or insurance companies.

Your WSIC Dashboard will only be shared with those involved in your care. The Data Protection Act says all organisations have to ensure they don't release information that could cause serious harm or distress to an individual. All care organisations involved in joined up care in North West London have to ensure they have checked all information before it is released to comply with the law.

# 17. Can I ask for my information to only be used for my individual care and not for other purposes?

It's not possible to request for your information to only be used for individual care on the WSIC Dashboard. If you don't want to share your information for other purposes, you'll need to opt-out of the whole dashboard.

Opt-out forms are available at your GP practice or online at:

http://integration.healthiernorthwestlondon.nhs.uk/informatics/information\_sharing

If you can't find a form in your GP reception, please ask the receptionist or your GP. Your GP will record your choice and your information will not be shared.

#### 18. How are patients involved in this programme?

Patients have been involved since the start of this programme, and continue to do so. There are patient communication groups and lay partners who represent patients' interests. Three patient representatives attend the Digital Governance Group who oversee this work and support patients' best interests.

#### 19. How are patients informed about this programme?

Information leaflets and posters are displayed in your GP practice, Local hospitals and Social Care and Community providers and links to information can be found here;

http://integration.healthiernorthwestlondon.nhs.uk/informatics

https://www.healthiernorthwestlondon.nhs.uk/

#### 20. What about the NHS National Opt-out Programme?

As of 25<sup>th</sup> May 2018, the NHS launched a programme whereby the public could set a preference on whether or not they wanted their confidential patient information used for research and planning. The WSIC system is used for direct care, planning and research purposes therefore any national opt out preference will be applied. If you opt out online, through your GP or hospital this will be respected, and your data will not flow into the



system.

You can find out more about the programme here: <u>https://www.nhs.uk/your-nhs-data-matters/</u>

#### 21. Can I get any information in another language?

For copies of this leaflet in Braille, audio CD or different languages contact us at <u>NWLCCGs.wsic.dashboards@nhs.net</u>

# 22. What Can I do if I am not happy or have a concern about how my data is being processed?

If you have any concerns, or are unhappy about how your data is being used please get in touch through any of the contact methods below:

Email: NWLCCGs.wsic.dashboards@nhs.net

Writing: WSIC Dashboards Team, NWL CCCGs, 2ndfloor, 15 Marylebone Road, London, NW1 5JD

Alternatively, you can raise a concern with the Information Commissioners Office (ICO) who are the UK data protection regulator who will investigate your complaint. Please see the Information Commissioner's website for more details: <u>https://ico.org.uk/concerns/</u>