

Privacy Notice - How we use Your Personal Data Patient/Service User Portal: My Care

Version 2.1

1. Introduction

This privacy notice provides comprehensive information about how your personal data is collected and processed when you use the **My Care** service user portal/app, which is part of the *encompass*¹ programme for Health and Social Care Northern Ireland (HSCNI).

We are committed to protecting your privacy and being transparent about how we use your information. This notice explains why we need your information, what personal data we collect, how it will be used, with whom it will be shared, and how long it will be kept.

2. Who we are

encompass is a Health and Social Care programme established to create a single digital health and care record for every citizen in Northern Ireland who receives health and social care.

¹ Encompass is an electronic health and care records system designed and built using a company called Epic.

Each Trust is "going live" with *encompass* at different times. You can find more information about the Go Live Dates on the encompass website: https://dhcni.hscni.net/digital-portfolio/encompass/

encompass provides a dedicated service user portal called **My Care** which can be accessed via a smartphone app or a website portal. This allows you to electronically access certain health and care information pertinent to your support, care and treatment including some of your medical history, upcoming appointments, healthcare reminders and test results.

My Care is not a tool for requesting or receiving urgent medical attention. If you or another service user are experiencing a medical emergency, please contact the appropriate urgent emergency services.

My Care is provided by HSCNI as part of the *encompass* programme. The Health and Social Care Trusts are the data controllers for the information processed through My Care.

The My Care patient portal is accessible by browser and mobile apps (Android and iOS). To login, you will download the MyChart by Epic app on Android or iOS/Apple, or login using the web browser. Inside the MyChart app there will be a dropdown list of Epic implementations. You will scroll to find My Care Health and Social Care and you can then log into the HSC portal through <u>nidirect</u>.

3. What information we collect

We only collect the information we need to. When you use **My Care**, we can collect and process the following types of personal information:

3.1 On your My Care App - Demographic information:

- Name (including preferred name)
- Date of birth
- Address (including temporary addresses)
- Contact details (phone number, email)
- Health and Care Number (HCN)
- Marital status
- Religion
- Language preferences

3.2 Health and care information:

encompass may also collect and record special category information for use as required by appropriate HSC staff, which may be viewable through **My Care** such as:

- Appointments (upcoming and past)
- Test results e.g. laboratory and radiology
- · Medications and allergies
- Care plans and treatment information
- Medical history and diagnoses
- · Letters and documents related to your care
- After Visit Summaries
- · Healthcare reminders

3.3 Information you can be asked to provide

- Messages to your care team where your care team have requested information to be submitted by you on a regular basis.
- Responses you give to questionnaires
- Updates to your personal information
- Documents you chose to upload (e.g., advance care plans)
- Self-reported medical, surgical, and family history
- User provided photograph

3.4 Usage information:

- Login dates and times
- · Pages viewed
- · Actions taken within the app
- System generated access and audit logs

3.5 Third-party information

You will be able to see:

- Upcoming medical appointments with location addresses (so you can find the right building to go to)
- High-level list of your care team (name, role, and specialty)

4. Is there any information that I cannot see?

Some information will not be available to view on the My Care portal. This includes disclosure of conditions, notes, patient interactions, and letters which are sensitive or cannot be shared with you if there is a concern for your welfare.

There are occasions when other people (for example, relatives, friends or carers) have provided information relating to your care. In some cases, there may also be information in your notes about other people that is their personal data. We have a duty to keep certain information confidential and may not be able to share it with you. This would not apply to health workers, social workers and education workers as per Schedule 2, Part 3, Paragraph 17 of Data Protection Act 2018. Each request will be assessed on a case-by-case basis.

Information not viewable on My Care includes:

- Mental health records (though some mental health information may be visible, e.g., in a medication list)
- Social care records
- Racial or ethnic origin

- Religious or philosophical beliefs (unless you choose to provide this)
- Information concerning sexual life / sexual orientation
- Historical test results and information (e.g., laboratory results, radiology reports, vital signs, cardiology reports, and endoscopy reports)
- Live information about an emergency episode or in-patient stay
- GP held data with the exemption of data provided as part of a referral.

5. How we collect your information for use with My Care

We collect your information in several ways:

- Directly from you when you register for and use My Care
- From your electronic health record held in the encompass system
- From the Northern Ireland Digital Identity Service (NIDIS) to confirm and verify your identity
- Automatically as you navigate through the My Care portal/app
- From your healthcare providers during your care and treatment
- From family members or carers, when necessary and appropriate

6. How we use your information to deliver the My Care service

We use your personal information to:

- Provide you with secure access to parts of your electronic health and care record within the encompass system.
- Allow you to view appointments
- Enable secure communication with your care team as agreed
- · Improve and personalise the My Care service
- Ensure the security and proper functioning of the My Care system

- · Communicate with you about appointments and ongoing care
- Improve services through safely shared, anonymised data for maintaining system security and audit purposes

7. Our lawful basis for processing your data

My Care processes your personal information to provide health and care services to you under a range of statutory functions and functions that are within the public interest. The lawful basis for My Care processing your data refers to the legitimate grounds upon which HSC may collect, use, and manage your personal data. It is a foundational principle of the UK General Data Protection Regulation (UK GDPR) Act that ensures our data processing activities are conducted with due regard for legality, fairness, and transparency. The detailed electronic health and care record processing is covered under a separate encompass Privacy Notice.

UK GDPR stipulates several conditions that qualify as a lawful bases, such as obtaining explicit consent, fulfilling contractual obligations, complying with legal responsibilities, protecting vital interests, performing tasks in the public interest, or pursuing legitimate interests of the data controller or a third party.

Our lawful bases for processing your personal data using My Care under the UK GDPR is:

 Article 6(1)(e) - Public task: the processing is necessary for us to perform a task in the public interest or for our official functions (provision of health and social care).

For special category health data², we rely on:

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² Special category data GDPR pertains to personal information that is inherently more sensitive and thus necessitates additional safeguards. This classification includes data that, if disclosed, could significantly infringe upon an individual's privacy and lead to discrimination. As such, GDPR mandates stringent protocols for processing such information to prevent misuse and protect the rights of individuals.

Article 9(2)(h) - Health and social care: processing is necessary
for the purposes of preventive or occupational medicine, for the
assessment of the working capacity of the employee, medical
diagnosis, the provision of health or social care or treatment or
the management of health or social care systems and services.

We are also obliged to comply with the following law and professional guidance:

- Health and Social Care (Reform) Act (Northern Ireland) 2009 (as amended) - www.legislation.gov.uk/nia/2009
- Department of Health Code of Practice on protecting the Confidentiality of Service User Information - https://www.health-ni.gov.uk/publications/code-practice-protecting-confidentiality-service-user-information

8. Who we share your information with (processing)

Your information in My Care is only accessible to:

- You and any Proxy (see section 9) you have authorised
- Your health and care team e.g. doctors, nurses, pharmacists, laboratory staff, social workers, therapists and other HSC staff involved in your treatment and care.
- Authorised HSCNI/BSO staff involved in supporting and maintaining the My Care system

All HSC staff are obliged within their contracts of employment, professional Codes of Conduct and by the common law Duty of Confidentiality to ensure that all personal data is treated with the highest possible levels of confidentiality. BSO, My Care Contractors and agency staff are also bound by contractual confidentiality obligations.

We use some third-party companies to host and support the My Care technical systems. These companies can only process your data in accordance with our instructions and include:

- Epic Systems Corporation and its subsidiaries
- InterSystems Corporation
- Microsoft (for Azure-based services)
- Telefónica Tech Northern Ireland Ltd.

Your information may be shared with healthcare providers within the UK for the purposes of your direct care. In some cases, your information may be shared with healthcare providers in other countries outside the UK which have the same electronic healthcare system, but only for the purpose of providing you with essential treatment and with your consent (e.g., if you are injured while on holiday).

There may be occasions where your information is shared with other approved organisations without your consent, but this will only happen when it is:

- Required by law
- Required by a Court Order
- Necessary to detect or prevent crime, including allegations or suspicions of fraud
- Necessary to protect the public from serious harm
- Required for monitoring certain health conditions

9. Proxy Access

You can access the My Care portal as a service user (to view your own health and care records) and / or you can decide to appoint a Proxy. A Proxy can access health and care records available through My Care on the service user's behalf. Proxy access may also be enabled by HSC Staff through My Care and is determined on the age, competency and capacity of the service user as required by law and guidance.

The following outlines the different ways that Proxy/Proxies can be enabled and access your record through My Care: -

- a) Any My Care user can enable Proxy Access
- b) Proxy access will only be granted by HSC staff if it is determined that it is appropriate and, in the individual's best interests.
- c) An individual with capacity may have more than one Proxy.
- d) Parent(s) or individual(s) with parental responsibility can have sole access to a child's My Care account from birth provided no concerns are identified.
- e) For individuals under 18, any person with parental responsibility may apply for access to their records through their HSC Team. Proxy access for those with parental responsibility is reviewed and monitored on a case-by-case basis involving discussions with the child/young person by their HSC professional.
- f) The names of individuals applying for Proxy access may be disclosed to others who hold parental responsibility for a child/young person.
- g) Parental proxy access will automatically expire when the service user reaches 18 years unless the individual is assessed to not have capacity or a best interest's decision is made that Proxy access should continue e.g. child or adult protection services or other considerations e.g. controllership.

Proxy access can also be enabled by any My Care user. The different levels of proxy access a service user can select are outlined in the system. The types of proxy depend on the service user relationship but can include:

- Next of kin
- · Parents of children
- · Legal Guardians
- Nominated friend

Proxies have to be nominated either by an HSC worker, or by the My Care user through My Care. The proxy will need to validate their identity through NIDIS identity checker on <u>nidirect</u>.

10. How will it affect me if I do not want to provide information?

The purpose of using your information through encompass and in input in My Care is to provide you with safe, fast and effective care. In order for encompass to provide this service for you we need to process some information about you and you cannot opt out of this processing. This processing and sharing of information allow encompass and or HSC services to provide you and others with appropriate care and protection.

However, you need to register for your own My Care account if you want to view your health & Care information using the patient portal or if you need to be established as a proxy for someone else's My Care account, e.g. if you are a parent of a child or carer for an adult with learning disabilities please contact your care team. If you do not want a My Care account, you are not obliged to register or activate your account.

11. How long we keep your information

We retain the information in My Care in line with the Department of Health's Good Management, Good Records (GMGR) retention schedules. The specific retention period depends on the type of information and its purpose. You can view the "Good Management, Good Records" section under "Disposal Schedule" on the Department of Health's website for more details.

12. How we protect your information

We take your privacy seriously. Staff will only access your information on a strict 'need to know' basis or when they are involved in your period of care. All staff have a legal duty to keep your information safe and confidential, as does anyone who receives information about you from encompass. In line with legislation My Care has a range of measures and strict standards to protect electronically held information. We have implemented appropriate technical and organisational measures (identical to *encompass*) to protect your personal data using My Care, including:

- Encryption of your data in transit and at rest
- Multi-factor authentication for user access to ensure only authorised users can access My Care.
- Regular security audits and penetration testing
- Staff training on data protection and information security
- Role-based access controls to limit data exposure
- Comprehensive disaster recovery and business continuity plans
- · Regular system backups and failover mechanisms
- Continuous secure monitoring and maintenance of IT systems

13. Your rights

Under UK GDPR and data protection law, you have certain rights in relation to the information and data we hold about you using My Care including:

- Right to access: You can request a copy of the information we hold about you. You have the right to submit a Subject Access Request to a Trust for a copy of your health and care record
- Right to rectification: You can ask us to correct any inaccurate or incomplete information.
- Right to erasure: In certain circumstances, you can ask us to delete your information.

- Right to restrict processing: You can ask us to limit the processing of your information in certain circumstances.
- Right to data portability: You can ask us to transfer your information to another organisation or to you, in certain circumstances.
- Right to object: You can object to our processing of your personal data in certain circumstances.

Detailed guidance on your rights and circumstances is available from the Information Commissioner's Office which can be accessed via this link: https://ico.org.uk/for-the-public/

If you wish to exercise any of these rights, please contact your relevant Trust (see details in Annex 1)

14. How to contact us and complain

If you have any questions about this privacy notice or how we handle your personal information in My Care, please contact your relevant Trust's Data Protection Officer.

You have the right to make a complaint at any time to the Information Commissioner's Office (ICO), the UK supervisory authority for data protection issues:

Information Commissioner's Office Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Tel: 0303 123 1113

Website: https://ico.org.uk/make-a-complaint/

15. Changes to this privacy notice

We keep this privacy notice under regular review and will place any updates on https://dhcni.hscni.net/digital-portfolio/encompass/my-care/. This privacy notice was last updated on 13 Aug 2024.

16. Accessibility

This information is available in various formats. Please contact bso.communications@hscni.net for details.

17. Additional Information

- You can opt out of receiving text message reminders by contacting the relevant booking office or informing the receptionist when you attend the clinic.
- If you choose to use other services provided by third parties in conjunction with My Care (such as location services), you do so at your own risk and subject to the terms and conditions of those services.
- We are currently working to resolve issues for under 17s registering for My Care. Until this is resolved, under 17s cannot access My Care (either as a User or a Proxy).

For more information about the encompass programme, please visit: https://dhcni.hscni.net/digital-portfolio/encompass/?csrt=225376311482321822

Annex 1

Organisation	Link to Privacy Notice
Belfast Health and	https://belfasttrust.hscni.net/about/access-to-
Social Care Trust	information/
Royal Victoria	
Hospital	
274 Grosvenor	
Road	
Belfast	
BT12 6BA	
Northern Health	https://www.northerntrust.hscni.net/about-the-
and Social Care	trust/accessing-information/
Trust	
Bretten Hall	
Bush Road	
Antrim	
BT41 2RL	
Southern Health	https://southerntrust.hscni.net/about-us/access-to-
and Social Care	information/
Trust	
Craigavon Area	
Hospital	
68 Lurgan Road	
Portadown	
Craigavon	
BT63 5QQ	
South Eastern	https://setrust.hscni.net/about-the-trust/access-to-
Health and Social	information/
Care Trust	
Upper	
Newtownards	
Road	
Dundonald	

Belfast BT16 1RH	
Western Health	https://westerntrust.hscni.net/about-the-trust/access-
and Social Care	to-information/
Trust	
MDEC Building	
Altnagelvin Area	
Hospital site	
Glenshane Road	
Londonderry	
BT47 6SB	