

Helm

Your health and care data under control

Privacy Notice

1. Overview

The Helm development project is led by Leeds City Council in partnership with the NHS organisations in Leeds and supports the integration of health and social care.

Organisations participating in the project are listed below:

Organisation the Helm project shares data with

- Leeds City Council (Data Controller)
- Leeds Teaching Hospital Trust
- Leeds NHS Clinical Commissioning Group
- GP Practices
- Leeds and York Partnership NHS Foundation Trust
- Leeds Community Healthcare NHS Trust
- Yorkshire Ambulance Service
- St Gemma's Hospice
- Wheatfields Hospice
- **Humber Teaching NHS Foundation Trust**
- **Rotherham NHS Foundation Trust**

Organisations the Helm project is in partnership with:

- NHS England
- NHS Digital
- UK Cloud
- Synanetics Ltd

2. Why we are processing data

Helm is a project developed in Leeds to enable citizens to have access to their own health and wellbeing information. By giving people more information about their own health and wellbeing and interactions with services, including the ability to contribute their own information, Helm will help people have greater control of their own decisions made about their health and care.

The legal framework governing the use of personal confidential data in healthcare is governed by the NHS Act 2006, the Health and Social Care Act 2012, data protection legislation and the Human Rights Act 1998.

Individuals participating in the initiative will contribute information in the form of "top three things to know about me". The information they contribute will be shared with health and social care professionals who will use this to inform their own decision making as well as help Helm users make more informed health and wellbeing decisions.

All information will be processed in accordance with the principles of Data Protection Act 2018 and GDPR.

Data you contribute to the Helm account

In order to create your account you will be asked to provide some demographic data. This will be used to populate your Helm account. This data will be stored on a secure remote system built by regional health and care organisations. We will ask your permission for us to transfer this data to the remote storage. You will be able to view this data every time you login into your account. **The sharing and storage of this data is governed by the Information Processing Agreement between Humber Teaching NHS Foundation Trust and Leeds City Council.** Some of this data will be used for evaluation of the project purposes and will be stored in a separate location on the Leeds City Council system. You will be asked to provide your permission for us to use your data in this way.

In addition your Helm account will contain information that you choose to contribute in the form of “top three things to know about me”. You will be given an option to ‘submit’ or ‘cancel’ the data you contribute to Helm. By submitting the information, the information will be stored on your Helm account maintained by the Leeds City Council and available to view by health and care professionals (with appropriate access permissions) via Leeds Care Record. By choosing to ‘cancel’, the data will be deleted and will not be saved on your account. You are responsible for the data that you contribute to your Helm account.

The data that is held on your account will be overwritten each time you update it. You and your health and care professionals can only view the latest version of that data. The overwritten data will then be stored in the archive part of Helm for the duration of your involvement with the programme. Access to this data will be limited to authorised staff only and can be accessed by you on request.

3. Verifying your Identity

To participate in the project and access your Helm record you will be required to verify your identity. You will only have to do this once, before you access Helm for the first time. This is to prevent fraud and ensure that you are who you say you are. Verification will be done by the NHS Login service. You will be required to go through a number of steps as instructed and provide a photographic proof of your identity. On completion, you will receive notification on your email to confirm that your identity has been verified and you can access your Helm account. The process may take up to 2 hours.

To access your Helm account you will have to type in your email address and password (this is the same password you used for your identity verification) followed by a four digit code which you will receive via a text message. This is known as a two factor verification.

Access to your Helm record will be via NHS Login each time you login into your Helm account. NHS Digital is the Data Controller for information you provide as part of your Identity check. You can view their Privacy Notice and T&C's on myhelm.org website.

4. Sharing information held on your Helm account

By signing up to Helm, you agree to share your data with health and care organisations specified in section 1. By sharing your data with these organisations, you are giving them permission to view what is held on your Helm record. Only health and care professionals directly involved in your care from within the organisations listed in section 1 will be able to see your information. They may choose to add the information onto their respective records they hold about you and use that information for the purpose of health and care they provide to you. In this case the health or care organisation will become the Data Controller of the data they record. The legal basis for processing that information by professionals in this way is covered by Article 9(2)(h) of the GDPR which permits processing of personal special category data for the purpose of provision of health or social care or treatment. Once the data has been added to your health and care records, it will form part of your medical record and different legal provisions governing these records and your rights will apply. For example, the data that has been put on your medical record held by health and care professionals will not be removed if you decide to withdraw from the Helm programme.

We may also share your information where it is necessary, for example, for fraud and crime prevention and investigation or where we are required to do so by law.

5. Data Quality and Assurance

It is important that the information you enter is accurate and up to date. You are responsible for accuracy of your data. This is because the data you contribute may be relied upon by health and care professionals when providing you with care. If you think you have entered data that is not accurate, you need to correct it immediately on your Helm record. Any data that has been overwritten will be stored in the archive of your Helm account for audit purposes and may be accessed by you on request. However, you will not be able to alter that record.

6. How do you know your records will be kept secure

Leeds City Council is leading on this project and acts as a Data Controller in respect of the data held on Helm, the system and its security. It is committed to taking all reasonable organisational and technical measures to ensure maximum security of personal data provided by you to Helm. The Helm system has been built in such a way as to ensure its use can be audited at any time. This allows confidentiality and access to be monitored where necessary. The data access is done via secure transmission between respective systems which are subject to adequate controls documented in respective data processing agreements.

The Helm platform is implemented in a secure cloud environment via UK Cloud which is subject to robust contractual arrangement with disaster recovery and contingency solutions as part of the service provision. You have responsibility for safety and security of the data stored on your account and are asked to ensure that your log-in details and passwords are kept secure at all times and not shared with anyone else.

All organisations that you share Information with are approved by Leeds Information Governance Steering Group and are signatories to the Information Sharing Agreement with robust confidentiality and security obligations. As Data Controllers, all organisations have appointed Data Protection Officers, who are responsible for monitoring compliance with data protection legislation, Senior Information Risk Owner (accountable for the management of all information assets) and a Caldicott Guardian (responsible for the management of patient information and patient confidentiality).

7. Your rights

You have a number of rights under data protection legislation which are applicable in relation to your Helm account. The rights marked with * (below) may not be applicable if you choose to exercise them in respect of your medical records held by health and care professionals.

Right to be Informed - You will be able to view the T&C's and Privacy notice as part of the enrolment process; the T&C's and Privacy notice acceptance 'acceptance tick box' will be presented for every login session. You will be mandated to acknowledge and accept changes to the T&C's and Privacy notices when there are updates.

Right to Access - You have the right to request access to your health and care records available to you through Helm. If you wish to access information held about you over and above that accessed through Helm you will need to submit a data subject access request to the relevant organisation that holds the information you require. If you wish to access data held in the Helm archive you will need to contact dpfoi@leeds.gov.uk.

Right to Rectification – This right applies when the information is inaccurate or incomplete. You have the right to request the controller to have the data completed and rectified. Where you input information inaccurately onto your Helm account and later decide to correct this information, please be aware that these changes may not necessarily be rectified in the individual organisations' systems and you will be expected to inform them of these changes directly.

Right to Erasure* ('right to be forgotten') - You have the right to request from the controller the erasure of personal data concerning you if the continued processing of those data is not justified. You will need to submit the request in writing.

The right to restrict processing - You have the right to request the restriction or suppression of your personal data. You can make a request for restriction verbally or in writing.

The right to data portability* - The right to data portability gives you the right to receive personal data you have provided to a controller in a structured, commonly used and machine readable format.

Right to object to Processing - The GDPR gives you the right to object to the processing of your personal data in certain circumstances, where processing is causing you substantial damage or distress. You can make an objection verbally or in writing.

Rights in relation to automated decision making and profiling* - There will be no automated decision making or profiling under this programme.

All enquiries in connection with exercising your rights in respect of data held on Helm should be submitted to Leeds City Council on dpfoi@leeds.gov.uk.

8. Withdrawing from the project

You can withdraw from participating in the project or in the evaluation at any time by contacting info@myhelm.org. Withdrawal from evaluation would mean that you will no longer be able to continue with the programme. Please note that if you decide not to participate in the programme we will not be able to retrieve any information which has already been used in the evaluation. Your views including the reasons for withdrawal would help us to evaluate the pilot.

9. Records Management

All the information inputted by you on Helm will be held in accordance with the Helm retention schedule. Live records will be held for the duration of your involvement with the programme. Where users have withdrawn from the programme or haven't used the account for twelve months, their accounts will be closed and the information stored on them will be removed from the system in accordance with the Helm Retention schedule.

All information gathered for the evaluation of the project will be retained by the Helm Project Team at Leeds City Council for a period of one year after submission of the final evaluation and then confidentially destroyed in accordance with the Council's Retention and Destruction protocol.

10. Complaints resolution

In the event where you wish to raise a complaint please contact info@myhelm.org.

11. Review

This Privacy Notice will be regularly reviewed to ensure it is up to date and accurate. You will be asked to review it next time you log into the system and accept it.

12. Data Protection Officer (DPO) - Louise Whitworth, Head of Information Management and Governance,
Address: Leeds City Council, Merrion House, 110 Merrion Way, Leeds, LS2 8BB
Email: DPO@leeds.gov.uk

13. Leeds City Council Privacy Notice - <https://www.leeds.gov.uk/privacy-statement/privacy-notice>

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Declaration

Leeds City Council (LCC) is the Data Controller for information stored on Helm. You are asked to read the information contained in the Helm Privacy and Consent form and provide your consent.

I consent to:

- Demographic data I contribute being shared with and stored on the system mentioned in Section 2 and I understand the purpose for which this information is going to be used.
- Information I contribute to my Helm account being viewed by health and care professionals directly involved in my care for the purpose of providing me with care.
- These organisations having the option to record the data contributed by me onto their clinical systems. I understand that this information will form part of my medical record and will be processed under a different legal status for the purpose of the provision of direct care.