

Appendix 1. Data collected using Jisc Online Surveys

The consent form and questionnaire surveys have been created using the 'Jisc Online Surveys' licence from the University of Leicester. As such, the University of Leicester acts as the Data Controller. Further information on the institution can be found here: <https://le.ac.uk/>. Jisc acts as the Data Processor, only processing the licensee's survey data in accordance with their instructions.

Online Surveys is certified to ISO 27001- the recognised information security standard. (<https://www.jisc.ac.uk/about/certification>). All Online Surveys user and respondent data is stored in the EU - for more information see: <https://www.onlinesurveys.ac.uk/help-support/online-surveys-security/>

The Data Protection Officer is: Elisabeth Taoudi, Data Protection Officer and Commercial Lawyer, University Of Leicester, University Road, Leicester, LE1 7RH. Tel: 0116 229 7640. Email: et177@leicester.ac.uk

This privacy notice explains how we use your personal information and your rights regarding that information

What information are we collecting?

Just like a paper consent form or paper questionnaire you may have been asked to fill in before, we are collecting information on your health and how it affects you. As the study is online, we are also testing whether an online consent form and online questionnaires are easier for people to fill in; as well as avoiding using lots of wasted paper. As you have expressed an interest in the study, we will already have the email address you emailed us on.

Along with the answers to the questions (either on the consent form or questionnaires), we will ask you for your full name (on the consent form), and date of birth, as well as your GP name and address (in the first section of the first questionnaire). We need your name and date of birth so we can access your medical records through your GP if appropriate. We will only use this information for these purposes and nothing else - it will not be associated with responses given or shared beyond the research team. After the first survey, you will not need to put this information again. Following your completion in the study, we will export the data from Jisc Online Surveys. When this is done, all data will be anonymised - you will not be identifiable from this - and the only identifier will be a unique study ID number which will be given to you.

Jisc Online Surveys is designed to protect your anonymity. Online surveys does not use cookies for survey completion and external tracking software such as Google Analytics is not supported on Online Surveys. Additionally, the research team cannot access any information about respondents' IP addresses.

Why are we collecting your data?

We are collecting data to look at whether an online educational programme can be beneficial in those with kidney problems.

How we will use this data?

Data collected may be published in a peer-reviewed medical journal and presented at appropriate medical meetings / conferences. No identifiable data will be presented in these reports.

What is the legal basis for processing the data?

The data will be processed under 'Consent', that is: you have given clear consent for us to process your personal data for a specific purpose.

How long we will process your data for?

Data will be stored under the University of Leicester Jisc Online Surveys licence and on secure University of Leicester IT systems. We will keep this data for 5 years after the end of the survey. All data will be deleted after this time.

What are your rights and how to enforce them?

Your participation in this survey is entirely voluntary and you can exit the study at any time. If you want to exit the survey you are completing, then simply close your web browser page. You do not have to answer any questions you do not want to. As a respondent you have the right to be forgotten and you may request that your response is deleted from the survey at any time. We believe there are no known risks associated with filling in any of the surveys; however, as with any online related activity the risk of a breach is always possible. To the best of our ability your participation in this survey will remain confidential.

How to complain to the Information Commissioner's Office?

The Information Commissioner can be contacted on:

Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire,
SK95AF

Tel: 0303 123 1113

Email contact can be made by accessing www.ico.org.uk

Appendix 2. Data collected using the 'My Kidneys & Me' programme

The 'My Kidneys & Me' programme, is hosted by the MyDESMOND e-learning platform (<https://www.desmond-project.org.uk/>). MyDESMOND is a service that has been created by the Leicester Diabetes Centre, for organisations licenced to the DESMOND National Programme.



Recently (in March 2020), MyDESMOND was adopted on the NHS Digital Apps library following extensive review against NHS Digital standards (more information can be found here:

<https://digital.nhs.uk/services/nhs-apps-library/guidance-for-health-app-developers-commissioners-and-assessors/how-we-assess-health-apps-and-digital-tools#how-the-assessment-works>).

This review by the NHS covered data protection, security, usability and accessibility, interoperability, and technical stability. The MyDESMOND platform was successfully adopted by NHS Digital meaning it passed all of the strict security and data protection tests needed by the NHS.

The Leicester Diabetes Centre is part of the University Hospitals of Leicester NHS Trust. You can find out how to contact us by visiting www.leicesterdiabetescentre.org.uk. University Hospitals of Leicester NHS Trust is registered as a "data controller" with the Information Commissioner's Office, under registration number Z7882087. Our Data Protection Officer is contactable through mydesmond@uhl-tr.nhs.uk or you can write to the Head of Privacy, University of Hospitals Leicester, Information Governance, County Hall, Glenfield, Leicester LE3 8RA.

Below are copies of the MyDESMOND 'Terms of Use', 'Privacy/Cookies Policy', and 'Acceptable Use Policy'. These are available online and links can be found at the bottom of the programme page at all times.

Please note that these statements cover the whole MyDESMOND platform, and as such, may mention terms such as diabetes or features that we have not decided to include in 'My Kidneys & Me' such as 'Ask the Expert'. You may also see references to being aged 13 years or over to use the programme; this is in reference to MyDESMOND which 'My Kidneys & Me' is part of and does not apply to participation in the current study which involves only adults.

After getting your unique link to the 'My Kidneys & Me' programme, and before registering to the programme, you will be asked that you have read these documents and agree to them. Whilst you do not have to read these in detail now, you will need to read and agree to them before registering to the 'My Kidneys & Me' programme.

Terms of Use

<https://www.mydesmond.com/terms-of-use>

If you have any immediate concerns in relation to your diabetes or the health of someone else you should not delay in contacting your doctor, another appropriate health professional or the emergency services directly on 999.

Information about us

MyDESMOND is operated by the University Hospitals of Leicester NHS Trust and via the Leicester Diabetes Centre. For enquiries about MyDESMOND, you can write to DESMOND, Leicester Diabetes Centre, Leicester General Hospital, Gwendolen Road, Leicester, LE5 4PW ("We").

www.mydesmond.com and www.desmond-project.org.uk are websites operated by The University Hospitals of Leicester NHS Trust.

We are regulated by the NHS Improvement and the Care Quality Commission.

PLEASE READ THESE TERMS OF USE CAREFULLY BEFORE USING THIS SITE

Terms of SITE use

These Terms of Use (together with the documents referred to) tells you the terms of use on which you may make use of our site MyDESMOND at www.mydesmond.com and related services (our site), whether as a guest or a registered user. Use of our site includes accessing, browsing, or registering to use our site.

Please read these Terms of Use carefully before you start to use our site, as these will apply to your use of our site. We recommend that you print a copy of them for future reference.

By using our site, you confirm that you accept these Terms of Use and that you agree to comply with them.

If you do not agree to these Terms of Use, you must not use our site.

Other applicable terms

These Terms of Use refer to the following additional documents, which also apply to your use of our site:

Our Privacy Policy, which explains how we process any personal data we collect from you, or that you provide to us when using our site.

Our Acceptable Use Policy, which sets out the permitted uses and prohibited uses of our site. When using our site, you must comply with this Acceptable Use Policy.

Our Cookie Policy:

The password protected areas of this site incorporates the use of cookies. Cookies are small data text files that are sent from a server computer during a browsing session. Cookies are

typically stored on your computer's hard drive and are used by site to simulate a continuous connection to that site. In order to make our site more responsive to your needs we use cookies to track and manage information relative to your specific requirements. In this way we can tailor our site to your needs, deliver a better and more personalised service and track the pages on our site that you visit. The use of cookies automatically identifies your browser to our computers whenever you interact with our site. Your browser options allow you to disable cookies. You should note that if you do disable cookies, you may not be able to access all the services on this site. You can find out more about cookies by visiting <https://ico.org.uk/for-the-public/online/cookies/>

Changes to these terms

We may revise these terms of use at any time by amending this page. Please check this page from time to time to take notice of any changes we made, as they are binding on you, a link to the Terms and Conditions can be found at the bottom of the page at all times.

Changes to our site

We may update our site from time to time, and may change the content at any time. However, please note that, because of the pace of medical progress, and changes made by other organisations beyond our control, any of the content on our site may become out of date at any given time, the content will be reviewed regularly and updated where applicable. We do not guarantee that our site, or any content on it, will be free from errors or omissions.

Accessing and use of our site

We do not guarantee that our site, or any content on it, will always be available or be uninterrupted. Access to our site is permitted on a temporary basis. We may suspend, withdraw, discontinue or change all or any part of our site without notice. We will not be liable to you if for any reason our site is unavailable at any time or for any period.

You are responsible for making all arrangements necessary for you to have access to our site.

You are also responsible for ensuring that all persons who access our site through your internet connection are aware of these terms of use and other applicable terms and conditions, and that they comply with them.

Our site is directed to people residing in the United Kingdom. We do not represent that content available on or through our site is appropriate or available in other locations. We may limit the availability of our site or any service or product described on our site to any person or geographic area at any time. If you choose to access our site from outside the United Kingdom, you do so at your own risk.

As a condition of your use of our site, you warrant to the Trust that you will not use the site for any purpose that is unlawful or prohibited by these Terms of Use, and notices.

You may not modify, copy, distribute, disable, transmit, display, perform, reproduce, publish, license, create derivative works from, transfer, or sell any information or services obtained from MyDESMOND. You may not use MyDESMOND for anything other than the purpose outlined

in these Terms of Use and you may not use spiders or other robotic software tools to gather information from the site or use any applications which could lead to harm to the site. You may not use the MyDESMOND service to indicate any association with MyDESMOND® or the Trust without the Trust's prior written consent.

You must be at least 13 years old to use MyDESMOND.

Your account and password

The main section of this site contains an e-learning platform, Self-Improvement Trackers and Action Plans for those with Type 2 Diabetes. If you wish to access this you will be sent an activation code from your local MyDESMOND Coordinator. Your use of the password protected areas of this site are subject to these terms of use.

If you choose, or you are provided with, a user activation code, password or any other piece of information as part of our security procedures, you must treat such information as confidential. You must not disclose it to any third party. You can find out more about online security at <https://www.getsafeonline.org/>

We have the right to disable any user password or account, whether chosen by you or allocated by us, at any time, if in our reasonable opinion you have failed to comply with any of the provisions of these terms of use.

You are responsible for all activity that takes place with your account. You may not authorise any third party to access and/or use the service on your behalf except where the Trust provides a mechanism for third parties to access the service on your behalf. If you know or suspect that anyone other than you knows your user password, you must promptly notify us at mydesmond@uhl-tr.nhs.uk.

Intellectual property rights

Product and company names mentioned on the site or other sites or services accessed through the site are owned by third parties. All contents of the site including these Terms of Use are the copyright of the Trust and are protected by other proprietary rights including database rights.

No part of the MyDESMOND service, including the site and any e-mail we send, may be reproduced in any form whether electronically or otherwise without the prior written consent of the Trust.

Those works are protected by copyright laws and treaties around the world. All such rights are reserved.

You must retain all copyright or trademark notices contained on this site on any copy you make of it or part of it. You may not sell or modify what is on the MyDESMOND service or reproduce, display, publicly perform, distribute, or otherwise use the content on it in any way for any public, academic, or commercial purpose. The use of such content on any other site or in a networked computer environment for any purpose is prohibited.

You may print off one copy, and may download extracts, of any page(s) from our site for your personal use. Apart from where the 'download' button is present, these items can be downloaded and printed as freely as the user wishes.

You must not modify the paper or digital copies of any materials you have printed off or downloaded in any way, and you must not use any illustrations, photographs, video or audio sequences or any graphics separately from any accompanying text.

Our status (and that of any identified contributors) as the authors of content on our site must always be acknowledged.

If you print off, copy or download any part of our site in breach of these terms of use, your right to use our site will cease immediately and you must, at our option, return or destroy any copies of the materials you have made.

No reliance on information

The content on our site is provided for general information only. It is not intended to amount to advice on which you should rely. You must obtain professional or specialist advice before taking, or refraining from, any action on the basis of the content on our site.

Although we make reasonable efforts to update the information on our site, we make no representations, warranties or guarantees, whether express or implied, that the content on our site is accurate, complete or up-to-date.

Limitation of our liability – PLEASE READ CAREFULLY!

Nothing in these terms of use excludes or limits our liability for death or personal injury arising from our negligence, or our fraud or fraudulent misrepresentation, or any other liability that cannot be excluded or limited by English law.

To the extent permitted by law, we exclude all conditions, warranties, representations or other terms which may apply to our site or any content on it, whether express or implied.

We will not be liable to any user for any loss or damage, whether in contract, tort (including negligence), breach of statutory duty, or otherwise, even if foreseeable, arising under or in connection with:

- use of, or inability to use, our site; or
- use of or reliance on any content displayed on our site.
- Please note that we only provide our site for domestic and private use. You agree not to use our site for any commercial or business purposes, and we have no liability to you for any loss of profit, loss of business, business interruption, or loss of business opportunity.

We will not be liable for any loss or damage caused by a virus, distributed denial-of-service attack, or other technologically harmful material that may infect your computer equipment, computer programs, data or other proprietary material due to your use of our site or to your

downloading of any content on it, or on any site linked to it. You can find out more about steps you can take to protect your computer against viruses and hacking at <https://www.getsafeonline.org>.

We assume no responsibility for the content of sites linked on our site. Such links should not be interpreted as endorsement by us of those linked sites. We will not be liable for any loss or damage that may arise from your use of them.

The main purpose of MyDESMOND is to provide information to users about information for Type 2 diabetes within the UK. All information provided via MyDESMOND is general information which can never be treated as being a substitute for professional health care. Do not rely upon any of the general information provided via the site for medical diagnosis or treatment. You must always consult with your doctor about personal health concerns.

If you have any immediate concerns in relation to your diabetes or the health of someone else you should not delay in contacting your doctor or the emergency services directly on 999.

Whilst the Trust does make every effort to check the accuracy of information published on MyDESMOND® it cannot give any warranty that information will be accurate or up-to-date and the user acknowledges that the information and services offered on MyDESMOND® may include inaccuracies, out of date information or typographical errors. In particular, and without limitation to the rest of this Agreement, the Trust is not able to guarantee that the MyDESMOND service will continue or be accurate during time of server failure.

Information contained in or accessible via MyDESMOND changes on a regular basis. The Trust may make improvements or alterations to MyDESMOND at any time without notice.

The Trust is not responsible in any way whatsoever for the content of any site accessed using the site, nor can it warrant that use of MyDESMOND will be free from virus contamination and you should take adequate steps to ensure that you virus check regularly when using MyDESMOND® on your computer, PDA, tablet, phone or any other device you may use to access the site.

The Trust makes no representations about the suitability of the information, and services contained on, or accessed via, MyDESMOND for any purpose. All warranties, terms and conditions with regard to this information, and services, including all warranties, terms and conditions, implied by statute, collaterally or otherwise, of satisfactory quality, fitness for a particular purpose, title, and non-infringement are excluded to the fullest extent permitted by law.

Ask the Expert

Our experts with experience in nutrition, exercise and diabetes prevention are available to answer your questions and support you in your health journey. This is a private feature and only you and our experts will see these messages. Please allow up to 2 business days for a response to your query. We are unable to provide individual medical advice and would recommend that you instead speak with your local healthcare professional.

Uploading content to our site

Whenever you make use of a feature that allows you to upload content to our site, or to make contact with other users of our site, you must comply with the content standards set out in our Acceptable Use Policy.

Viruses

We do not guarantee that our site will be secure or free from bugs or viruses. You are responsible for configuring your information technology, computer programmes and platform in order to access our site. You should use your own virus protection software. You must not misuse our site by knowingly introducing viruses, Trojans, worms, logic bombs or other material which is malicious or technologically harmful. You must not attempt to gain unauthorised access to our site, the server on which our site is stored or any server, computer or database connected to our site. You must not attack our site via a denial-of-service attack or a distributed denial-of service attack. By breaching this provision, you would commit a criminal offence under the Computer Misuse Act 1990. We will report any such breach to the relevant law enforcement authorities and we will co-operate with those authorities by disclosing your identity to them. In the event of such a breach, your right to use our site will cease immediately.

Linking to our site

The links provided from the site have been authorised by the Trust. If you would like to add a link to the site, you require written consent from the Trust. If you would like information about obtaining the Trust's permission to use any content of MyDESMOND or if you would like to link your site to MyDESMOND, please write to: MyDESMOND Steering Group c/o DESMOND Director, Leicester Diabetes Centre, Leicester general Hospital, Gwendolen Road, LEICESTER, LE5 4PW.

In the event that any consent is given by the Trust to create a link to the site, you must ensure that you do so in a way that is fair and legal and does not damage our reputation or take advantage of it.

You must not establish a link in such a way as to suggest any form of association, approval or endorsement on our part where none exists.

You must not establish a link to our site in any site that is not owned by you.

Our site must not be framed on any other site.

We reserve the right to withdraw linking permission without notice and we shall not be obliged to give a reason for doing so.

The site in which you are linking must comply in all respects with the content standards set out in our Acceptable Use Policy.

If you become concerned about the content of a site linked to or from the site (or anything on the site), please inform the Trust immediately via e-mail to mydesmond@uhl-tr.nhs.uk.

If your complaint is about unsuitable content you may also consider reporting the matter to the Internet Watch Foundation who can be contacted via their Web site at www.iwf.org.uk.

Third party links and resources in our site

Where our site contains links to other sites and resources provided by third parties, these links are provided for your information only.

We have no control over the contents of those sites or resources.

A reference on the site to any persons, products, web sites or services does not constitute or imply their endorsement, recommendation or favouring by the Trust.

VARIATIONS OF THESE TERMS OF USE

The Trust reserves the right to change these Terms of Use and notices under which the site is offered. We will do this by altering these Terms of Use on the site and this alteration will then be of immediate effect. For this reason, you should regularly visit these Terms of Use on the site as the current version will be binding on you. We may bring changes directly to your attention.

Applicable law

If you are a consumer, please note that these Terms of Use, its subject matter and its formation, are governed by English law. You and we both agree to that the courts of England and Wales will have exclusive jurisdiction. In using the services available on this site, you will at all times obey all applicable laws.

If you are a business, these Terms of Use, its subject matter and its formation (and any non-contractual disputes or claims) are governed by English law. We both agree to the exclusive jurisdiction of the courts of England and Wales.

In operating this site the Trust adheres to relevant statutory duties and best practice guidance listed below. This list is not exhaustive but provides the legal and professional frameworks upon which the site is reviewed on an on-going basis:

- General Data Protection Regulation
- Data Protection Act 2018
- Information Commissioner's Office guidance
- Freedom of Information Act 2000
- Human Rights Act 1998
- NHS Information security management guidance
- Common law of confidence
- Caldicott Guardianship
- NHS Code of Confidentiality
- NHS Code of Practice: Information Security Management

GENERAL

You agree that no joint venture, partnership, employment, or agency relationship exists between you and the Trust as a result of these Terms of Use or use of the site. Each and every provision of these Terms of Use is separate and severable. If any part of these Terms of Use is

determined to be invalid or unenforceable pursuant to applicable law including, but not limited to, the warranty disclaimers and liability limitations set out above, then the validity and enforceability of the remainder of the these Terms of Use shall not be affected.

These Terms of Use constitutes the entire agreement between you and the Trust with respect to the site and it supersedes all prior or contemporaneous communications and proposals, whether electronic, oral, or written, between you and the Trust with respect to the site. A printed version of these Terms of Use and of any notice given in electronic form shall be admissible in judicial or administrative proceedings based upon or relating to these Terms of Use to the same extent and subject to the same conditions as other business documents and records originally generated and maintained in printed form. Any rights expressly granted herein are reserved. You will be responsible for all charges, fees, duties, taxes, and assessments arising out of your use of the site.

Contact us

To contact us, please mydesmond@uhl-tr.nhs.uk

Thank you for visiting our site.

MyDESMOND Acceptable Use Policy

<https://www.mydesmond.com/acceptable-use>

This acceptable use policy sets out the terms between you and us under which you may access our website www.mydesmond.com (our site). This acceptable use policy applies to all users of, and visitors to, our site.

Your use of our site means that you accept, and agree to abide by, all the policies in this acceptable use policy, which supplement our terms of website use.

MyDESMOND is operated by the University Hospitals of Leicester NHS Trust via the Leicester Diabetes Centre. For enquiries about MyDESMOND, you can write to MyDESMOND, Leicester Diabetes Centre, Leicester general Hospital, Gwendolen Road, LEICESTER, LE5 4PW. www.mydesmond.com is a site operated by The University Hospitals of Leicester NHS Trust ("We").

We are regulated by NHS Improvement and the Care Quality Commission.

Prohibited uses

You may use our site only for lawful purposes. You may not use our site:

- In any way that breaches any applicable local, national or international law or regulation.
- In any way that is unlawful or fraudulent, or has any unlawful or fraudulent purpose or effect.
- For the purpose of harming or attempting to harm minors in any way.

- To transmit, or procure the sending of, any unsolicited or unauthorised advertising or promotional material or any other form of similar solicitation (spam).
- To knowingly transmit any data, send or upload any material that contains viruses, Trojan horses, worms, time-bombs, keystroke loggers, spyware, adware or any other harmful programs or similar computer code designed to adversely affect the operation of any computer software or hardware.

You also agree:

- Not to reproduce, duplicate copy or re-sell any part of our site in contravention of the provisions of our terms of website use.
- Not to access without authority, interfere with, damage or disrupt: any part of our site;
- any equipment or network on which our site is stored;
- any software used in the provision of our site; or
- any equipment or network or software owned or used by any third party.
- Suspension and termination

We will determine, in our discretion, whether there has been a breach of this acceptable use policy through your use of our site. When a breach of this policy has occurred, we may take such action as we deem appropriate.

Failure to comply with this acceptable use policy constitutes a material breach of the terms of use upon which you are permitted to use our site, and may result in our taking all or any of the following actions:

- Immediate, temporary or permanent withdrawal of your right to use our site.
- Immediate, temporary or permanent removal of any posting or material uploaded by you to our site.
- Issue of a warning to you.
- Legal proceedings against you for reimbursement of all costs on an indemnity basis (including, but not limited to, reasonable administrative and legal costs) resulting from the breach.
- Further legal action against you.
- Disclosure of such information to law enforcement authorities as we reasonably feel is necessary, as set out in our Privacy Policy.
- We exclude liability for actions taken in response to breaches of this acceptable use policy. The responses described in this policy are not limited, and we may take any other action we reasonably deem appropriate.

Changes to the acceptable use policy

We may revise this acceptable use policy at any time by amending this page (available here after via the 'Terms and Conditions' link at the bottom of all pages). You are expected to check this policy from time to time to take notice of any changes we make, as they are legally binding on you. Some of the provisions contained in this acceptable use policy may also be superseded by provisions or notices published elsewhere on our site.

MyDESMOND Privacy/Cookies Policy

<https://www.mydesmond.com/privacy-policy>

If you are a MyDESMOND user or subscriber, or just visiting our website, this policy applies to you. This Privacy Policy will help you understand what information we collect, why we collect it and what we do with it.

Who we are

MyDESMOND is a service that has been created by the Leicester Diabetes Centre, for organisations licenced to the DESMOND National Programme. The Leicester Diabetes Centre is part of the University Hospitals of Leicester NHS Trust. You can find out how to contact us by visiting www.leicesterdiabetescentre.org.uk.

University Hospitals of Leicester NHS Trust is registered as a “data controller” with the Information Commissioner’s Office, under registration number Z7882087.

Our Data Protection Officer is contactable through mydesmond@uhl-tr.nhs.uk or you can write to the Head of Privacy, University of Hospitals Leicester, Information Governance, County Hall, Glenfield, Leicester LE3 8RA]

Why we need information from you

We hope that by using MyDESMOND you will be better able to understand and manage your Type 2 diabetes. The e-learning section of MyDESMOND allows you to learn more about Type 2 diabetes through a range of interactive sessions, and the self-management trackers allow you to update, track and manage a range of health-related measures (e.g. blood pressure & cholesterol), as well as activity and diet levels. The action plan section of MyDESMOND allows you to create and review plans for lifestyle changes relevant to you. You can input information about your goals and get emails to remind you of your progress.

We need information from you in order to personalise these services for you. This includes information about age, ethnicity, and other risk factors associated with Type 2 diabetes. If you do not provide this information, this will reduce the accuracy and relevance of the content on MyDESMOND.

The information that we collect about you

Your local DESMOND Organisation will receive your details from your GP or Practice Nurse in order to invite you to use the MyDESMOND website, or you may receive an invitation from an existing user as part of the “buddies” feature of the programme.

We then collect two kinds of information once you start using MyDESMOND:

Information you give us:

- You give us information by registering, logging in to, and using the MyDESMOND site, by filling in and updating forms on MyDESMOND and responding to questions. The information you give us may include:

- your name,
- address,
- e-mail address,
- phone number,
- ethnicity and date of birth,
- as well as information about your health and wellbeing that you submit through interacting with the MyDESMOND site.
- We use this information to provide the personalised MyDESMOND service to you. Depending on the information you enter, the logic behind MyDESMOND will show you different information in consequence, based on clinical guidance (age and ethnicity are risk factors associated with Type 2 diabetes). You can resubmit or vary information if you like – but MyDESMOND will work best when the information you submit accurately reflects your health experience.

Information we gain through how you use the site (cookies)

Cookies are small files placed on your computer that collect standard internet log information and visitor behaviour. We use this information to track visitor use of the website and compile statistical reports on activity. You can find out more by visiting <https://ico.org.uk/for-the-public/online/cookies/>. You can set your web-browser not to accept cookies, but this might impact on some of the features of the website.

Our website uses Google Analytics, a service which transmits website traffic data to Google servers in the United States, and which we then use to make the site work and to understand how it is being used. Google Analytics does not identify individual users or associate your IP address with any other data held by Google. We use reports provided by Google Analytics to help us understand website traffic and webpage usage. The way in which Google operates Google Analytics is set out in Google's Privacy Policy- external site. You can opt out of Google Analytics if you disable or refuse the cookie, disable JavaScript, or use the opt-out service provided by Google- external site; however by opting out, the site may not function correctly.

What we do – and don't do – with information about you

We will:

- store the information you provide so that you can continue to access and make use of the MyDESMOND website;
- make available your information with your local DESMOND Organisation as part of your direct care;
- provide access to an administration area of the website for your local DESMOND Organisation to download/extract your name, date of birth, practice and NHS number;
- Advise your local DESMOND Organisation to ensure they abide by all NHS standards for handling identifiable information;
- Advise your local DESMOND Organisation to use the extracted data to match against your routine care records (this will include HbA1c/blood glucose levels);

- Be sent an anonymous and password-protected version of the matched data from each local DESMOND Organisation, which will be analysed for audit purposes and stored in accordance with NHS standards for record handling.
- Provide access to a forum and chat functionality where you can choose to chat and share information with other users, if you want.
- Provide access to a secure messaging system which allows you to securely and confidentially send questions to experts at the Leicester Diabetes Centre. Your username will be attached to your message, and your message will only be viewed by admin staff and the expert who answers your question.
- Provide you with the ability to sync your MyDESMOND account with Fitbit or Google Fit. If you choose to sync your account then we will share the information you have provided with Fitbit or Google. Their use of your data is governed by their own privacy policies, rather than ours – see:

<https://www.fitbit.com/uk/legal/privacy-policy>

<https://policies.google.com/privacy>

We may:

- use the anonymous information your local DESMOND Organisation give us as part of internal clinical audit, to measure or understand the effectiveness of the MyDESMOND service that we offer to you and others;
- use the information you give us as part of the administration of MyDESMOND and for internal operations, such as troubleshooting, so as to improve our site and ensure that content is presented in the most effective manner for you and others using MyDESMOND;
- need to share information about your use of the site with our web hosting company and our web developers, but only to the extent that is needed for the running and maintenance of the MyDESMOND website. Where possible this will not include any information which could be used to identify you personally. Our webhosting company and developers are subject to strict obligations of confidentiality and won't be able to use your data for anything else.
- ask you from time to time about your experience in using MyDESMOND and use the information you provide to analyse and improve the service we offer you;
- need to share your information with other organisations as part of our legal compliance obligations: for instance, the Care Quality Commission inspects the Trust regularly and can ask to see the information we hold.
- need to use your information in connection with legal proceedings, or to investigate and respond to any complaints you may make.

We don't:

- share information with other users of the website.
- share the information you give us with any commercial organisations not previously mentioned.

The legal basis for processing your information

“Processing” means doing anything with your information, for example collecting, storing or deleting your information. Data protection law means that we can only use your data for certain reasons and where we have a legal basis to do so. Here are the reasons for which we process your data:

The processing is necessary for us to comply with our legal obligations, such as obligations to provide a safe service. We are under legal obligations to have systems in place to proper records (under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014; MyDESMOND is a service provided by the Trust as part of the NHS and forms part of the exercise of our functions under the NHS Act 2006, which include the supply of health services.

Because our service is a ‘health’ service, we will also process ‘sensitive’ information (known as “special category personal data”). The normal legal basis for this is:

- The processing is necessary for the purposes of preventive medicine, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services;
- processing is necessary for reasons of public interest in the area of public health, such as ensuring high standards of quality and safety of health care.

We will respect your confidentiality and wherever possible, we will respect your wishes in terms of how we use your information.

Keeping your information up to date

It’s really important that the information you give us is kept up-to-date, so that you can monitor your progress yourself and so that those with an interest in your health, such as your GP, can find out how you are getting on. You can keep your information up-to-date:

- by changing your information on your MyDESMOND account page – click on the link on the top right of any page – , and
- on the specific information you provide on, for instance, your BMI, blood glucose, and activity logs – click on the dashboard on the top left of any page.

How long we keep your information for, and when you stop using MyDESMOND

We keep information on your account for 24 months if the account remains active. If the account is deactivated or unused all information is archived after six months, and permanently deleted after 24 months. This is so that we meet our compliance obligations, and in case you want to use the service again in the future. You can find out more about the retention periods for healthcare related information in the NHS Records Management Code of Practice, available via <https://www.gov.uk/government/publications/records-management-nhs-code-of-practice>

Keeping your information safe and secure and where your data is stored

We use a range of physical, technical and organisational security measures and processes to keep your information safe and secure, such as:

- password login;
- encryption on our website;
- carrying out regular privacy impact assessments
- training for staff on information security and data protection;

- restricting the number of staff that can see identifiable information you provide to the website, only to those that need to know or see the information in order to do their jobs.
- Our servers are based in the UK, but your data may be transferred outside of the UK where you have chosen to sync your account with Google Fit, or Fitbit, or where you have not opted-out of Google Analytics. This is because Fitbit and Google use servers which are outside of the UK and your information will be stored on these servers. You can find out more about Fitbit's privacy policy (<https://www.fitbit.com/uk/legal/privacy-policy>) or Google's privacy policy (<https://policies.google.com/privacy>).

You can find out more about how the NHS keeps online information safe, and what you can do to help with this, by reading the guidance note at <http://www.nhs.uk/nhsengland/thenhs/records/healthrecords/documents/patientguidancebooklet.pdf>

Please remember:

- You provide information at your own risk: unfortunately, no data transmission is guaranteed to be 100% secure;
- You are responsible of your username and password: keep them safe and secure!
- If you believe your privacy has been breached or infringed, please contact us immediately by emailing mydesmond@uhl-tr.nhs.uk

Your rights

You have control over much of the information you supply to us by choosing what you input into the MyDESMOND system. You can limit this but this may mean that the MyDESMOND service does not work well and may give you an inaccurate picture of your diabetes.

You also have the right to:

- ask us to let you know what information we hold about you
- ask us to amend the information we hold about you if you think it is incorrect
- ask us to delete any information we hold about you
- ask us to limit the way in which we use your information
- ask us to send your information on to a third party
- make a complaint to the Information Commissioner's Office about the way in which we have used your information. The ICO can be contacted by visiting <https://ico.org.uk>.
- You should be however be aware that the accuracy and relevance of the programme will depend on the level of information you provide to us.

We will not make a charge in the first instance for providing you with the information we hold about you or.

You can contact our Data Protection Officer to find out more about how we use your information or to exercise any of your rights mentioned above. Our Data Protection Officer is contactable through mydesmond@uhl-tr.nhs.uk or you can write to the Head of Privacy, University of Hospitals Leicester, Information Governance, County Hall, Glenfield, Leicester LE3 8RA.

Children

You must be aged 13 or above to use MyDESMOND.

Changes to this policy

Any changes we may make to this privacy policy in the future will be posted on this page and, where appropriate, notified to you by e-mail. Please check back frequently to see any updates or changes to our privacy policy. This page was last updated on 10/07/18.

How to contact us

You can contact us by emailing mydesmond@uhl-tr.nhs.uk with any questions or concerns. You can also use the 'feedback' button on every page to email us with comments about the site.