



Patient information

Consent 4 Consent Information

Research, Development and Innovation

What is Consent 4 Consent?

The Liverpool University Hospitals NHS Trust (The Trust) has developed a secure database, called “Consent 4 Consent” (C4C), of volunteers who are willing to be contacted about future research studies. Volunteers include those with or without medical conditions.

Why do we need volunteers for research?

Research is the only way to improve our understanding of illness and to build evidence to develop better treatments in the future. Nearly all research needs the help of volunteers in order to develop these procedures and find out whether they are effective.

As a research hospital we have a range of research studies taking place, from clinical trials of new medicines to questionnaire based studies.

How do I join C4C?

If you would like to join the C4C database please complete a consent form and we will add you to the database. This is completely voluntary; you can choose to be removed from the database at any point. Once on the database The Trust staff will contact you periodically (every two to three years) to check if you still wish to remain on it and to update your records if appropriate.

What data will you collect and store?

The C4C team will collect and store the information about you that you disclose on the consent form. This information will include your name, date of birth, contact details and health information (height and weight, medical conditions, smoking status, allergies and medication) which is regarded as a special category of information.

This information is required to allow us to review your initial eligibility for research studies and then contact you with further information. If your information, such as contact details or medication changes, we will update this with your permission.

Who will have access to my data?

The C4C team and research teams from The Trust will be the only people to have access to your information. They will be the ones to approach you regarding any research. Your information is solely used for research purposes within the trust and your contact details will never be passed on to any third party or company.

The Recruitment Manager will act as the data controller for The Trust and can be contacted on Tel: 0151 706 4863 or via C4C@rlbuht.nhs.uk.

What will you use my data for?

Your data will be used for research purposes which fall into the public interest category under the General Data Protection Regulations. Your data will be held on a secure database here at the hospital. Should a study open in the hospital, that may be relevant to your condition, you may be contacted by research staff to ask if you would consider joining the study.

How will my data be stored?

Your information will be stored on a secure database within the hospital. It is password protected and only accessible by the C4C team. Research Teams must apply for information which will be transferred securely once approved.

How long will you store my data for?

The C4C team will contact you every two to three years to check whether you are happy to remain on the database. If after several attempts, we are unable to contact you then your data will be removed from the database and the paper consent form destroyed. You are able to re-consent at a later date should you wish to.

If I sign up today what am I actually agreeing to?

By agreeing to give us your contact details today you are saying that you are happy for research staff in the hospital to contact you should a research study require volunteers. If you are a patient at The Trust you may give permission for research teams to check your medical notes to see if you are eligible for a particular research study.

We will also send you a newsletter with information about upcoming research opportunities, feedback from research studies and relevant news stories. You may opt out of this on the consent form. Opting out of the newsletter will not affect you being contacted for research studies.

Can I change my mind?

Yes - You can change your mind and have your details removed from our C4C database at any time, without this affecting your healthcare.

If I decide not to go ahead with C4C will this affect my treatment?

No - Should you decide that you do not wish to be a part of the C4C database this will have no effect on the treatment that you receive from the health care professionals within the hospital.

I'm currently taking medication, can I take part?

You can still join the C4C database and be considered for individual research studies. You may still be eligible depending on what type of medication you take – it also depends on the type of research and what the investigator is looking for.

What happens if there are any changes to my health or contact information?

If your contact details change or you have any significant changes to your medical conditions, you can inform the C4C team (using the contact details below) who will update your information accordingly.

What should I do if I want to make a complaint?

If you want to make a complaint about the way we have handled your personal data then please contact Sharon Brislen (Data Protection Officer) on Tel: 0151 706 3671 or via dpo@rlbuht.nhs.uk.

If you are not happy with the response you have the right to raise your concerns with the Information Commissioner's Office. Information about how to do this can be found on their website at www.ico.org.uk or by calling Tel: 0303 123 1113.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

For any other questions you may have, please feel free to contact the C4C team using the details below or view our website on:

www.clinicalresearchliverpool.nihr.ac.uk

C4C Team

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Prescot Steet
Liverpool,
L7 8XP**

**Contact e-mail: c4c@rlbuht.nhs.uk Telephone: 0151 706 4860
Text: 07342 065915**

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All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل انتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والإلكترونية.

所有經信托基金批准的患者資訊均可以其它格式提供，包括其它語言、易讀閱讀軟件、大字體、音頻、盲文、穆恩體 (Moon) 盲文和電子格式，敬請索取。

در صورت تمایل می‌توانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانیاری پیوندیدار بهو نه‌خوشانه‌ی له‌لایم تراستهوه پسمند کراون، نگمر داوا بکرنیت له فورماته‌کانی تردا بریتی له زمانه‌کانی تر، نیزی رید (هاسان خویندنه‌وه)، چاپی گموره، شریتی دهنگ، هیلی موون و نملیکترونیکی همیه.

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Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhadda kale, sida luqadda kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.