Homeless Link

Using In-Form to influence national change

The HOME Study: FAQs

in-form
by Homeless Link

King's College London

University of Salford Manchester

LSE CPEC

UCL

UK Health Security Agency

Homeless Link

Expert Focus Teaching

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Bradford Institute for Health Research
Making Research Real

FAQs

About the study

What is the HOME study?

The HOME study, or Housing Model Evaluation, is a multi-year, multi-partnership research study looking to better understand how different homelessness accommodation models, and experiences of homelessness, impact on health outcomes.

The main aim of the research is to provide policy makers and planners with information necessary to design systems to improve the health of people experiencing homelessness. And this will be delivered through three objectives:

- Understand Context and Mechanisms through which different housing models act to improve health
- Describe the economic costs and benefits of different housing models
- Describe the impact on health and mortality

There are three core workstreams that are delivering this: multi-sited ethnography (deep dive, place based qualitative engagement across multiple services in a number of local areas); economic case studies; and data linkage.

The data linkage is the critical part of the research and is the part that involves In-Form. The aim of the HOME study is to take In-Form data and link it to NHS hospital episode data and mortality data. Because In-Form is captured by all different accommodation and service types it will help us understand how health outcomes change depending on who is in what housing setting, how different models help to improve health outcomes, the impact of people not being able to access suitable housing options and more.

Who is involved?

There are lots of partners across the whole of the HOME project. These include: UCL, LSE, Kings College London, Salford University, Bradford Institute for Health Research, UKHSA, Homeless Link, Expert Focus, and Southwark Council.

The team working on the data linkage strand of the work are from UCL, UKHSA, Bradford Institute for Health Research, Homeless Link and Expert Focus.

The project team includes some of the most highly regarded health inequalities academics and specialists in the country including Professor Andrew Hayward and Dr Dan Lewer.

How is it funded?

The research is funded through the National Institute for Health Research (NIHR). You can see the full research bid and details on the NIHR website here.

How long is the research project?

The initial project is funded for three years.

When does the project start?

The project has already started! It actually started back in March 2023 and some of the other strands of the project are well underway. The data linkage workstream has been spending the last few years making sure we have the ethical and legal approvals to conduct the work we're proposing to undertake. Now we have all this in place we are finally kicking of this phase of the research: recruiting In-Form users to take part in the study.

Who can take part

Which services are included in the study?

The primary focus of the research is how different homelessness accommodation models impact on health outcomes so the main services we are targeting are homeless accommodation providers. This includes any and all accommodation services including (but not exclusive to): nightshelters, crashpads, hostels, supported accommodation, temporary accommodation, Housing First, floating support etc. If you're not sure if your service counts then you can get in touch with cate.standing-tattersall@homelesslink.org.uk to ask.

We are also interested in understanding people's health before they access accommodation including people who are rough sleeping, sofa surfing or experiencing other extreme forms of homelessness. This means we're also interested in day centre services who will be working with people in these circumstances.

My service isn't in the list. Can we not take part?

Due to the rigour of the data protection and legal protections we've put in place to conduct this research we have had to be very specific about which services we include. This means at this stage we can only access data from homelessness specific accommodation services or day centres.

If you think your service is relevant but is not currently included in the above list then do get in touch to discuss further.

Not all the services we provide are homeless services. What happens then?

We know that lots of organisations provide some homeless specific services but also non-homelessness services. For example if you provide homelessness accommodation alongside domestic abuse refuge, disability accommodation, and general needs housing. In this case you would still be welcome to take part but we would only be interested in the data from the homeless services. We have the ability to only extract the data that is from those services and not touch the data from your wider organisation.

What data will be collected

What data will you be extracting from In-Form?

For each organisation that agrees to participate in the study we will be extracting individual client data of everyone who has access your relevant services. But we won't be extracting everything you collect! We are only interested in very specific information. This includes:

- Identifiable information so that we can do the data linking. This would be name, DOB, NHS number (if known) etc.
- Timelines so that we can understand the time period that people were in different services or circumstances where recorded.
- Housing situation so that we can understand current, and historic (where possible) information on people's housing and homelessness history. This will include fields like history of rough sleeping.
- Support needs so that we can better understand the wider needs of people beyond the clinical health data
- Demographics so that we can understand if outcomes are different for different populations

We will not be extracting any case notes or detailed information from key worker or anything related to support planning including outcomes star data or other progress tools. We will also not be extracting any financial information from e.g. rent modules where applicable.

If you want to know the full detail of what will and won't be extracted please contact cate.standing-tattersall@homelesslink.org.uk to set up a meeting to discuss further.

What timeframe of data will you be using?

We are interested in both current and historical data that you have stored on In-Form. This means that we will agree a date that we are going to perform the data extract and we will be extracting all available and relevant data prior to that date.

For example, if you started using In-Form in February 2018 and we agreed an extract date of 1st September 2025 we would extracting data from February 2018 – 1st September 2025 inclusive.

What about people who don't want to take part?

The data approvals we have mean we are able to operate an opt-out rather than an opt-in process. This means we don't have to get individual consent to use date but that doesn't mean we shouldn't provide people the opportunity to opt-out if they don't want to take part in the study.

We have been working with a lived experience group to develop a meaningful opt-out process for people to tell us they don't want to take part. This includes multiple ways of contacting us: via email, phone, text, WhatsApp or webform. And we will be asking participating services to put up a poster to inform people of the study and how to opt-out. We also have a website explaining more about the study and how to opt-out including videos explaining the process, what will happen to their data and the data protection processes in place.

People will have a lengthy window to opt-out but once the data has been linked the identifiable data will be deleted and therefore we will no longer be able to find people to remove them.

What about information about our service / organisation?

We will be collecting some information about your service and organisation. This is to help categorise your service so we can understand what type of provider you are. For example if we want to understand the difference that a nightshelter versus a Housing First provider might make on health outcomes we need to know enough about your service to categorise this. We will do this by asking you to complete a brief audit form that will help us group you with comparable services across the country.

The name of your service will be kept during the data linkage period to help us identify people who want to opt-out but once the data has been linked and anonymised this will be deleted.

Any analysis and reporting will be done at a grouped service level rather than individual services so the name of your service or organisation will not be included at all and no one will be able to identify your service.

What happens to the data

What will Homeless Link do with our data?

Once you've signed up to take part in the study and completed the relevant Data Sharing Agreement the Homeless Link research team will then extract the relevant data from the backend of the In-Form system.

We will then need to do some tidying up of the data including making sure we are using consistent field names so that we can create a big merged dataset of all the services and organisations who are taking part. We will create this dataset and then send it securely to the data linkage team at UCL and UKHSA who will be doing the next phase of the research.

Will I have to create reports or help with getting the data out?
No! All we need from you is permission to extract the data and for you to sign a Data Sharing Agreement, we will do the rest. You don't need to create or run any reports from your side – we will do it all from the backend of the system.

What happens once the data are shared with the data linkage team?
Once we've shared the aggregated dataset the data linkage team will do a little bit more tidying to help get it in shape to be linked. This will include finding and merging the records of people who appear multiple times in the data through different services so that we can create as complete as possible timelines for people.

Once this is done the data will be entered into the NHS digital Personal Demographic Service (PDS). At this point identifiable data from In-Form such as name and date of birth will be used to link people to their NHS numbers. Once we've matched people to their NHS numbers we will delete the other personal information.

The data with the NHS number attached will then be linked with Hospital Episode data (HES) and mortality data. Once we have matched the HES and mortality data the NHS numbers will be destroyed and the information will be anonymised. For each individual we will be left with their homelessness housing timelines and their health experiences overlaid on top (including before and after they accessed support) but we won't know who they are. We will have some broad demographic data such as gender, age range etc. but there will be no personal identifiable data left.

At this point the team will start their analysis.

Data protection

Is it not against the law to share individual data on the people we support?
This is a really important question and we don't underestimate how big an ask it is to share this kind of data. If we hadn't got the permissions to do this research it would be against the law for us to ask, and for you to share this data with us in the way we're asking for. But the research team have been working very hard on securing the correct legal permissions and protections that allow us to conduct this research including extracting the data at individual level.

For most of the work many / most of us do the legal basis that we use to utilise people's data is consent. This means we get individuals to actively give us permission to use their data – whether this is to record it for service records, share it with other providers or use it for research purposes. Many people mistakenly think that organisations *must* get consent to process personal data. In fact, consent is just one of six lawful grounds for processing data and this research will be operating under one of the other lawful grounds amongst other special permission that we have received. One of the other grounds is based on the public value of a research study and the value of this project in helping us understand health inequalities and improve health outcomes means there's legal basis to use In-Form data.

We are operating under a number of UK GDPR and Data Protection Act principles that give us the legal basis under which we are conducting this research. This means data will be processed using the following obligations:

- UK GDPR Article 6(1)(e) 'processing is necessary for the performance of a task carried out in the public interest'
- UK GDPR Article 9(2)(i) 'processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health'
- Data Protection Act Schedule 1 Part 1 (3) 'public health'

This is the legal basis through which we have permission to carry out this research without gaining individual consent, and everyone taking part in the study, including you, will be protected under. This has been confirmed and verified by data protection experts at UCL and UKHSA who have been advising us throughout.

In addition we have also been given special permission under Section 251 of the NHS Act 2006, as granted by the Confidentiality Advisory Group (CAG)giving lawful basis to set aside the common law duty of confidentiality without individual consent, so that the data we are requesting can be shared without breaching confidentiality. This means we can operate under an opt-out principle rather than opt-in – people are included by default unless the tell us otherwise.

All we would need is for you to review and sign a Data Sharing Agreement. This would allow Homeless Link to process your organisation's client data from the In-Form system and share it with UCL and UKHSA. The Data Sharing Agreement has been drafted by data protection specialists at UKHSA.

Throughout this whole process we have been engaging heavily with the UKHSA data protection teams who are experts in data protection and our legal duties. Through the above obligations, special permission and advice and guidance received we are secure in our knowledge that we are legally allowed to do all part of this data linkage research.

If it's opt-out not opt-in how do people say they don't want to take part?

It is not possible to ask the tens of thousands of people included in homeless accommodation and national health datasets for individual consent to use their data in these ways.

The data approvals and legal basis that we are operating under mean we are able to operate an opt-out rather than an opt-in process (see above). This means we don’t have to get individual consent to use date but that doesn’t mean we shouldn’t provide people the opportunity to opt-out if they don’t want to take part in the study.

We have been working with a lived experience group to develop a meaningful opt-out process for people to tell us they don’t want to take part. This includes multiple ways of contacting us: via email, phone, text, WhatsApp or webform. And we will be asking participating services, and other targeted services and forums, to put up a poster to maximise our reach in informing people about the study and how to opt-out. We also have a website explaining more about the study and how to opt-out including videos explaining the process, what will happen to their data and the data protection processes in place.

People will have a lengthy window to opt-out but once the data has been linked the identifiable data will be deleted and therefore we will no longer be able to find people to remove them.

How will you make sure the data is safe and secure?
Even though we’re using a different legal basis to access the data we are still obliged to secure, process and protect the data exactly as you would expect.

On the Homeless Link side once the data are extracted they will be held in a secure folder on our site. This will be password protected and only accessible by the research team. We will then be sharing the data using a secure file sharing system called Egress Protect. This is a file encryption tool that secures sensitive data during transmission and ensures that only authorised recipients can access the information.

Once shared with the team at UCL and UKHSA it will again be held in a secure, password protected folder and only accessible by named members of the project research team.

No one outside of the project research team will be able to access the data at any point. And once data are no longer needed by different parts of the team access will be shut off, and any held data deleted.

We will be deleting identifiable data at the earliest opportunity following the data linkage.

Lived experience engagement

Have you involved people with lived experience in this project?
Yes. It is important to us that just because we have the legal permission to do this research that we also make sure we have the ethical and moral considerations of using people's information in this way. We have been working with Expert Focus, a lived experience organisation to run a series of engagement workshops to understand the opinions of people with current and recent experiences of homelessness. This is really important to us and we wouldn't have progressed the project without their opinion and go ahead.

What do they think about it all?
Generally speaking people are very supportive of the research and it's aims and intentions. People want to see the health impact of homelessness taken more seriously, and for people to invest more in the quality services that make a difference. They understand that getting individual consent would be impossible and once they were reassured that the data would ultimately be anonymised and nothing about them as individuals would be published they were accepting of the data linkage approach. They did have concerns about wanting to make sure as many people as possible had the chance to opt-out if they didn't want to take part.

But ultimately they welcomed the study and were keen to be part of it – the general opinion was if their experience can help improve things for others then that's a good thing.

What have you changed based on their feedback?
The big thing that the lived experience group told us was that we needed to strengthen the opt-out offer to make it as easy and accessible as possible. So we have done this. Under their guidance we have created multiple different ways that people can opt-out depending on their preference: they can leave a voicemail, send a text or WhatsApp, send an email, or complete a webform. And we have streamlined the information they need to share with us to opt-out to make it as easy as possible.

We have also created posters that participating services can put up to advertise the study, share some information about it and steer people to the opt-out options. There are two versions of this poster: a standard one and an easy read version.

The lived experience group also asked that we create a website page that people could visit to find out more on their own time, and with more detail than the poster. We have done this which includes some videos created by people with lived experience giving more information about the study and lots of detail about what happens to their data so they can make an informed decision about whether they want to opt-out or not.

What do I / my organisation have to do?

How do I find out more about taking part in the research?

You can get in touch with the project team at Homeless Link who are more than happy to arrange a meeting with you to discuss the study and answer any questions you may have about your service's involvement. Please contact them via email: cate.standing-tattersall@homelesslink.org.uk or sophie.boobis@homelesslink.org.uk

If I sign up what do I / my organisation have to do?

Signing up doesn't require you do to any work with the actual data but there are a few things you will need to do. These are:

1. Sign a **data sharing agreement** (this has already been drafted by data protection specialists, so you just need to review and sign).
2. Sign a **letter of instruction** (which has already been drafted by data protection specialists) which will allow Homeless Link to access your service's In-Form records.
3. Fill out a **short questionnaire** on what type of accommodation service you are and what support you provide.
4. We will ask you to display a **poster** in your service which explains what the study is about, and the opt-out process if service users wish to do so.

The relevant documents will be sent to you via email once you have registered your interest in taking part. After you have signed the documents, we do not require anything else from you or your service. We will keep you updated on the study and share all the outputs and impact that you would have helped shape.

Is there a deadline to sign up?

We're recruiting organisations and services to participate on a rolling basis. The hard deadline to sign up will be December 2025.

I want to take part! Who should I contact?

You can register your interest in taking part by emailing Cate, who is a researcher on the project, cate.standing-tattersall@homelesslink.org.uk

We will then take you through the next steps.

What We Do

Homeless Link is the national membership charity for frontline homelessness services. We work to improve services through research, guidance and learning, and campaign for policy change that will ensure everyone has a place to call home and the support they need to keep it.

Homeless Link

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