

Public consultation on the use of confidential patient information without consent within the UK Colorectal Cancer Intelligence Hub

Key Messages

- 75 people attended one of four public consultation sessions.
- The majority supported the intended use of confidential patient information without consent, with only two 'no' votes.
- The sessions identified key areas for ongoing consultation during the lifetime of the project.

Background

In October 2023, an application was submitted (reference number 23/CAG/0151) to the Health Research Authority's Confidentiality Advisory Group (CAG) to request support for use of confidential patient information in the COloRECTal cancer data Repository (CORECT-R) within the UK Colorectal Cancer Intelligence Hub. CAG provided provisional support but requested that further consultation was undertaken to investigate patient and public views on whether such use was acceptable. The research team have now completed this consultation and this report provides details of the both the process and the findings of the four consultation sessions undertaken.

Recruiting participants

Four online sessions were advertised as widely as possible to try and ensure a representative sample of patients and the public. The advert/invitation used is provided in Appendix 1. The organisations it was sent to included:

1. Bowel Cancer UK
2. Cancer Research UK
3. UseMYdata
4. Yorkshire Cancer Research
5. Macmillan Cancer Support
6. Black Health Initiative (Leeds)
7. Guts UK
8. Shine Cancer Support
9. Black Women Rising
10. Sakoon Through Cancer
11. National Institute of Health Research (NIHR) Oxford Biomedical Research Centre mailing list
12. NIHR People in Research
13. Nuffield Department of Population Health Patient and Public Involvement Team
14. Centre for Research Equity at Primary Care Health
15. NIHR Royal Marsden Biomedical Research Centre
16. Oxford University Hospitals Trust Patient and Public Group
17. NIHR Clinical Research Networks – Thames Valley
18. NIHR Clinical research Networks Research Champions
19. South Asian Health Research Group
20. The Leanne Pero Foundation

21. Black Thrive (Lambeth)
22. Healthwatch groups in Oxfordshire, Buckinghamshire, Milton Keynes, Surrey, West Berkshire, Reading, the Midlands and London
23. 43 other local groups in the Midlands, Thames Valley and London

These organisations were asked to share the invitation on their social media channels, advertise it in their newsletters and on their patient/public forums and networks.

Registered participants

A total of 90 people registered to participate in the events with 75 attending. The characteristics of this population (taken from the registration form), and their location within the UK, are provided in Table 1. More detailed information on patient demographics, such as ethnicity, was not captured due to the potential sensitivity of this information.

Table 1: Characteristics of the people who registered to participate in the sessions

	Characteristic	n
Gender	Female	67
	Male	20
	Other or not reported	3
Age	18 - 25	3
	26- 34	9
	35 - 44	5
	45 - 54	21
	55 - 64	23
	65 - 74	19
	75+	10
County/Country	East Midlands	3
	East of England	3
	England*	10
	London	10
	North East	3
	North West	7
	Scotland*	4
	South East	21
	South West	5
	UK*	8
	Wales*	3
	West Midlands	3
	Yorkshire and the Humber	10
Have you had a cancer diagnosis	No	61
	Yes	27
	I prefer not to say	2
Total number of registered participants		90

*The form asked for county of residence but some participants provided country only

Patient and Public Consultation Sessions

All participants were sent a pre-read document (see Appendix 2) outlining the purpose of the meeting and the topics that would be discussed. A facilitator, who was independent to the research team, hosted the events. The format consisted of a 15-minute presentation (Appendix 3) delivered by one of the principal investigators of the project followed by approximately 45 minutes discussion of the proposed use of patient information within the project. At the end of the meeting an anonymous poll was undertaken asking the question:

Do you support the proposed use of confidential patient information without consent for this project?

Response options were Yes, No and Unsure.

Across the four sessions, the 75 participants engaged in lively discussions with a wide range of views expressed. The key outcomes from the sessions are highlighted below.

Poll

The summary measure of the level of public support for the use of confidential medical information in this project was provided by an anonymous poll at the end of the meetings. They indicated strong support, with the majority of respondents answering positively (Table 2). Not all participants participated in the poll, however, and it became apparent that not all could see the voting tool. This appeared to be dependent on the type of device they were using to access the session. If they could not see the poll, and they were happy to do so, people were asked to give their vote in the text 'chat' section. It is possible that some of the people who gave no responses felt uncomfortable voting via the chat since it would not be anonymous. However, it was clearly expressed in the sessions that honest opinions were being sought and that the facilitator was independent of the research team.

Table 2: Responses from the poll on whether attendees supported the use of confidential patient information without consent for this project

Session	Attendees	Poll Response			
		Yes*	No	Unsure	No response
1	20	11	0	0	9
2	22	18	0	0	4
3	17	14	0	0	3
4	16	9	2	1	4
Total	75	52	2	1	20

*Includes people who voted using both the polling tool and in the chat of the meeting

Many attendees felt the research programme was of great importance:

“We desperately need to improve cancer outcomes in the UK... If we could only use this data in a more intelligent way and make it more accessible to researchers, we could in fact make a significant difference to patients and their families. And that, to me, is the ultimate justification for this.”

“Big data is the only way we're ever going to start levelling up. You know the care that's given to everybody in this country and until you can start investigating things like, are people disadvantaged because they don't live near a teaching hospital.”

“There's just so much that we could gain by looking at big bulk data. My personal view is if you want the NHS to fix you, you ought to be willing to chip in with your data for research and planning, as long as it has really stringent safeguarding conditions.”

“I think it's really important that we have a full picture because there's so much health inequality around the UK...”

“We can optimise the use to have it be done securely, with a new system that be more streamlined because not only would that mean the current research can be done more effectively, but also it will free up time and resources for the future and bring further benefit to public health outcomes.”

“Data security is important, but people's health and ability to survive is arguably more important. I would encourage people to think about what are the risks of not optimising the use of patient data.”

There were several common themes that arose across the sessions that have provided the CORECT-R team with insight into areas where further information, or ongoing consultation, may be needed. These common themes included:

1. Transparency

There was a consistent call from participants to be as transparent as possible in what information was included in the system, who accesses it and what the information would be used for. Participants also asked for thought to be given on how to reach those who do not have English as a first language. Participants told us:

“The word data needs a big PR campaign. When you say data, everybody talks about leak and privacy etc. It's got such negative connotations and people don't necessarily see the benefits of this.”

“The strategy of reaching out to those groups of people that are mostly passive needs to be thought about, because language barrier alone can be a hinder and this can be dealt with by use of knowledgeable community reps who know how to penetrate them better.”

2. Opt-outs

There was a widespread feeling that the current system of opt-outs was confusing and unwieldy. For example:

“You might opt out of something when it may not be wholly relevant to you... you can sometimes change your mind on what data is being shared and what you're willing to be involved with. I don't know how to opt back in once I've opted out.”

A few participants questioned whether opt-outs were even necessary whilst others asked if a national opt-in process was possible. The team hosting the event were asked many questions about the national data opt-out, primary care opt-outs, cancer registry opt-outs and project specific opt-outs. Queries included how they relate to each other and how opt-outs operate in practice. The team acknowledged that understanding opt-outs was challenging but explained that CORECT-R had to operate within the existing system. The team stated that the relevant opt-outs would be clearly explained on the Hub website.

3. Concern regarding possible commercial access

Many of the participants asked if information would be provided to commercial companies. The team explained that this may happen in the future but would be dependent on agreements with data providers such as NHS England. Some participants expressed a strong distrust in the use of medical information by commercial companies and were keen to avoid this. For example:

“What is the potential of that data then being sold to private companies?”

“What people are worried about is that the information is going to be used for gain rather than to benefit the public and the patients...”

The team explained that access to any information within the proposed system would be overseen by an independent panel, which would include patient and public representatives, and would only be granted for purposes that would help inform colorectal cancer and outcome. In addition, the team described the information security mechanisms to protect the information within the system.

4. Uncertainty of funding

The current funding stream for this project is set to end in March 2025 and this was noted by some participants, and, in consequence, they raised questions about the sustainability of the system. For example:

“If you get the go ahead to have this secure data system, how long will you be able to support the security of that?”

The team explained that, whilst this funding stream was ending, there were many other initiatives underway which this system would complement, and other funding streams were being investigated. Also, that the system was intended to increase efficiency in NHS information flows rather than create another ‘silo’. As such, concerns about sustainability were answered satisfactorily.

Ongoing public consultation

We do not consider this consultation to be the end of the discussion with patients and the public. We intend to continue with the plan for wider consultation that is noted in our original CAG application. However, we do intend to revise our consultation plan to consider the issues of transparency, opt-outs, and commercial use as raised in the session

discussions. We are also committed to supporting our existing Patient-Public Group. We would leave the last word to a participant:

“For research purposes, whilst I think its brilliant idea how all these big data can join together, going forward, people should be informed of how the data has been gathered and people are not being dehumanised. We are not just data.”

Appendix 1 – Invitation

Confidential medical records and bowel cancer research. WE WANT TO HEAR YOUR VIEWS

We want to know what people think about access to patient records to help bowel cancer research. **You are invited to join an online session to find out more and join a discussion.**

Bowel cancer is a common disease with over 41,000 people being diagnosed with it, and 16,000 dying from it, every year in the UK. Unfortunately, the chances of surviving from bowel cancer in the UK are lower than in other similar countries and there may be a 'postcode lottery' in treatment and outcome across the National Health Service (NHS).

Our team conducts research using healthcare records. These records contain a lot of information about every person's cancer and their medical care. Although a lot of information exists, it is stored in lots of different places. This makes it hard for researchers to look at all the information at once and slows down, or stops, the research.

We would like to join up the different sets of medical records. The University of Oxford is being funded by Cancer Research UK to find out how this can be done. But before we can do that, we need to ask patients and members of the public what they think about how we use the data.

We are running a series of online sessions so that we can hear from you. Each session will be an hour long. It will be run by a facilitator from Cancer Research UK who is not a member of the research team.

- ⇒ **To attend you just need to be over 18 and able to participate online via Teams.**
- ⇒ **No previous understanding or experience of cancer, data or research is required.**
- ⇒ **We encourage people from all backgrounds to attend and share their thoughts.**

Sessions:

- 2-3pm on Tuesday 6th February 2024
- 6-7pm on Tuesday 6th February 2024
- 10-11am on Thursday 8th February 2024
- 12:30-1.30pm on Friday 9th February 2024

To register for one of the sessions:

please visit: <https://forms.office.com/e/TJgMmfjjPi>

Each session will start with a short presentation. The study team will be available throughout the session to answer queries. You will simply be asked what you think about a proposed approach to joining up information. There are no right or wrong answers. Some brief background reading will be sent out before the session to help you prepare.

We can offer a payment of £25 as a thank you for taking part.

For more information, please contact oxfordcancerppi@medsci.ox.ac.uk

Appendix 2 – Pre-read**Pre-reading for confidential medical records and bowel cancer research Patient and Public Involvement sessions****Background information**

Bowel cancer is a common disease with over 41,000 people being diagnosed with it, and 16,000 dying, every year in the UK. Unfortunately, the chances of surviving bowel cancer in the UK are lower than in other similar countries and there is a 'postcode lottery' in treatment and outcome across the National Health Service (NHS). A team in Oxford is doing research to try and make sure everyone gets the best care possible and more people survive this disease.

They do this research using healthcare records. These contain a lot of information about every person's cancer and their medical care. Although a lot of information exists in the NHS, it is stored in lots of different places. This makes it hard for researchers to look at all the information at once and slows down, or even stops, the research.

What data linkage is proposed?

The team at the University of Oxford have been given money by Cancer Research UK to try and join up the different sets of information and then use the linked data for research. This is difficult because to link the datasets it is often necessary to use information such as a patient's NHS number, their date of birth, or postcode so that records in each of the different datasets that belong to the same person can be linked. Such data items are personal to an individual and there are laws to make sure they are kept confidential as much as possible. But if they are kept completely secret, it is not possible to link the datasets up and they can't be used for research. Also, because so many patients are involved, it is not possible to seek their consent individually for linking their records.

Why do my views matter?

An organisation called the Health Research Authority's Confidentiality Advisory Group (CAG) oversees who can have permission to use confidential patient data. They will only allow the research team to use the data if they feel the benefits of the work outweigh the risks. As part of making this decision, CAG have asked this research team to talk to patients and the public about whether their data should be used in the way suggested above. These sessions are a way of gaining your views.

What will happen in the session?

To give us your views you will need to understand what data the research team would like to use, how they will handle it to make sure it remains secure, and what are the risks and benefits of the research. At the start of each session there will be a short presentation from the research team

explaining these things. Then an independent person unconnected to the research will start a conversation with all the people at the session about whether they feel it is OK for patient data to be used in the way the research team suggest. The research team will remain in the session to answer any questions, but it is your views that they want to hear, no matter whether you agree or not with the research suggested.

If you would like to know more about CAG, and what they do, information is available via their website: <https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/>

Appendix 3 – presentation



Confidential medical records and bowel cancer research – what are your views?

February 2023

Eva Morris & Amy Downing

Bowel cancer

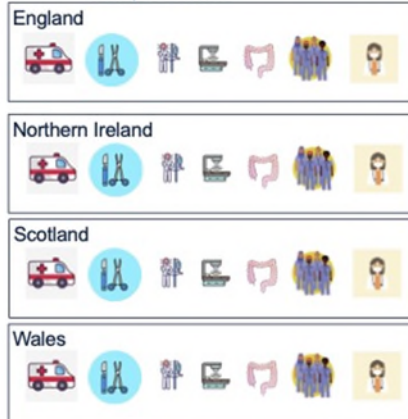
Cases	Deaths	Survival
42,886	16,808	53%
		
New cases of bowel cancer each year, 2016-2018 average, UK.	Deaths from bowel cancer, 2017-2019, UK.	Survive bowel cancer for 10 or more years, 2013-2017, England

Health data

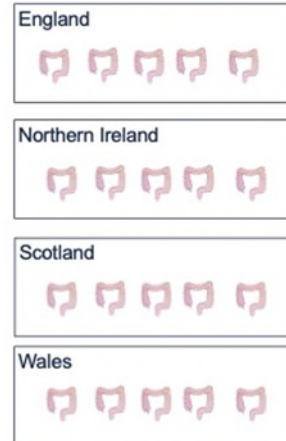
GP practices



Hospital data



UK Cancer Registries

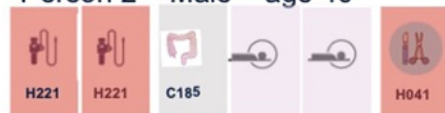


Examples

Person 1 – Female – age 45

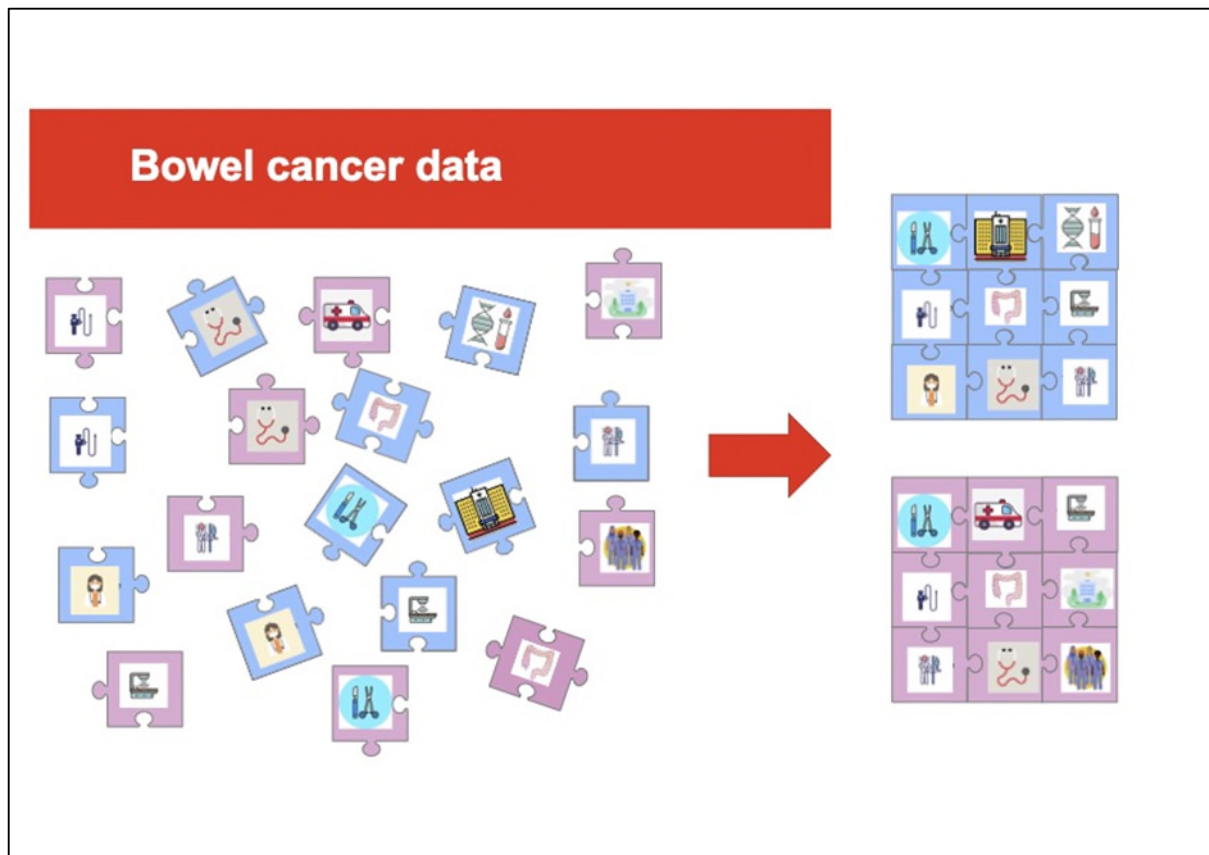


Person 2 – Male – age 49




Person 3 – Female – age 51

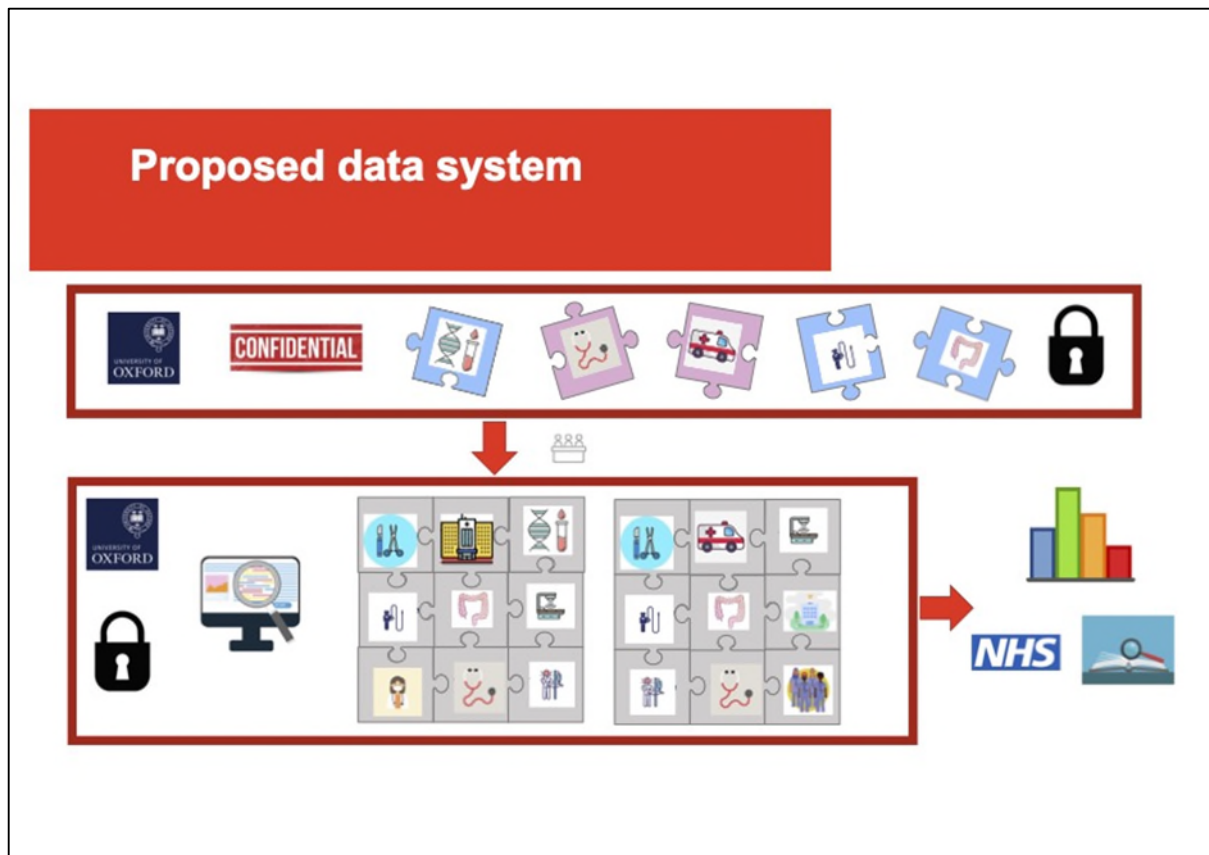




Current NHS data systems



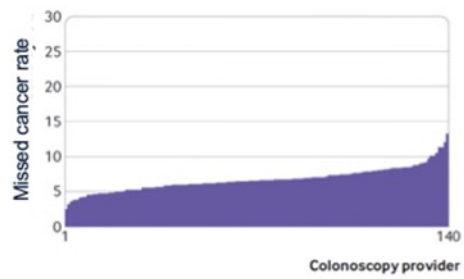
- Currently NHS data is held and managed separately in England, Northern Ireland, Wales and Scotland
- Cancer does not respect these boundaries
- If a research project needs to use UK data, they have to apply to at least 4 different organisations to request access.
- These processes are lengthy and costly and not an efficient use of resource
- Our proposal is to create a single data system for the UK
- But, when designing this system, we must remember that:
 - There are already good data systems that work for some types of research
 - Researchers do NOT need direct access to patient identifiers



Risks

- Data are accidentally released
- Data are stolen
- Data are accessed by insurance or banking companies or someone else without permission

Benefits



Opt-outs

Choice

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Question



Do you support the proposed use of confidential patient information without consent for this project?