Insight Report: "Innovative, automated use of real-world healthcare data to improve outcomes for patients with ovarian cancer" project online public involvement session

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Contents

SUGGESTED CITATION

Background

The National Institute for Health Research (NIHR) currently funds 20 Biomedical Research Centres (BRCs) across England. These are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics, and medical technologies. The Imperial BRC is a collaboration between Imperial College, London and Imperial College Healthcare NHS Trust and is currently funded until November 2022. It has 12 research themes, 4 of which are cross cutting. The Cancer theme is one of these 12 themes.

To assist with a project entitled "Innovative, automated use of real-world healthcare data to improve outcomes for patients with ovarian cancer" being undertaken by this theme, the Imperial Patient Experience Research Centre (PERC), a core facility of the Imperial BRC facilitated an online discussion session on ovarian cancer and health data led by Dr Laura Tookman, Dr Amit Samani and Ben Glampson.

Public Involvement is defined by the NIHR as "research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them"[1]

"Public" includes patients, potential patients, carers and people who use health and social care services as well as people from specific communities and from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they're current patients or not.

Approach and purpose

Public involvement is considered a crucial component of all BRC research projects. As part of this online session the research team wanted to understand the following from individuals with lived experience of ovarian cancer (both patients and carers) in order that these insights could shape and improve this project:

a) How they thought the team could use (anonymised) Imperial Clinical Analytics, Research and Evaluation (ICARE) data to improve care for all patients with ovarian cancer

b) What they thought the reasons are for inequalities in access to equal care, and what data could be looked at to explore these inequalities

c) How they thought the team could use/should have used (anonymised) data to improve their care

Call overview and agenda

An online discussion was hosted on Wednesday 27th April 2022 from 5.30pm to 7pm via Zoom Pro.

The aims of this particular online session were to:

1. Introduce the Imperial Biomedical Research Centre and the research project theme (5 mins)

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[1] https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#:~:text=NIHR%20defines%20public%20involvement%20in,that%20influences%20and%20shapes%20research.

2. Explain the purpose of the project, its timeline and proposed public involvement plan
3. Give attendees an opportunity to ask questions (15 mins)
4. Facilitate small group discussions in Zoom break-out rooms about the following questions (45 mins):
   a) How do you think we could use (anonymised) data to improve care for all patients with ovarian cancer?
      i. Do you think this data could be used to help the healthcare team looking after patients with ovarian cancer?
   b) We know that not all patients with ovarian cancer have access to equal care. These inequalities may affect the treatment given and overall outcome.
      i. Can you think of reasons for these inequalities in care?
      ii. What data could we look at to explore these inequalities?
   c) How do you think we could use/should have used (anonymised) data to improve your care?
      i. What information/statistics would you like to know about all patients with ovarian cancer to support you during your diagnosis and care?
      ii. What information would you like to have access to about your own/loved one's cancer?
      iii. How would these have helped you manage your condition?

After an introduction was provided to the project and to the planned public involvement throughout, attendees were given an opportunity to ask questions (see **Appendix 2**) before being split into two break-out rooms using Zoom Pro to have smaller group discussions about their responses to the questions above. Each break-out room was hosted by a researcher and a public involvement facilitator. A chemotherapy nurse was present during the session to provide any psychological support which might have been required by the attendees. Questions asked in each break- out room are included at **Appendices 3 and 4**.

Attendee recruitment
Efforts were made to bring together members of the public who had lived experience of ovarian cancer either personally or as a carer. This was undertaken by disseminating the opportunity through Ovarian Cancer Action and through cancer clinics at Imperial College Healthcare NHS Trust. There were 19 attendees (17 patients and 2 carers)(see **Appendix 1** for demographics of attendees).

Feedback
Following the session, attendees were sent an anonymous online feedback form to comment on ways the session could be improved and to give any additional views on the questions posed in the session (see **Appendix 5**). Comments relating to the questions discussed in the session were integrated into the report summary.

Payment
In accordance with NIHR payment guidance, participants were paid £42.50 for their time including a £5 contribution to Wi-Fi/data for accessing a virtual meeting.

Key Insights Summary

Insights raised during the breakout room discussions have been themed under the three main questions posed and are summarised below.

How do you think we could use (anonymised) data to improve care for <u>all</u> patients with ovarian cancer? Do you think this data could be used to help the healthcare team looking after patients with ovarian cancer?

Attendees' responses centred around the following themes: that they **supported** the **use of anonymised data** for this purpose especially the use of **ethnicity, age** and **location** data to **identify risk factors** for ovarian cancer e.g., working night shifts. However, the **accuracy of data** was considered paramount, and examples were provided of hospital records being inaccurate. Attendees expressed a need for patients to be able to **correct inaccuracies in their own data** with the example given of the system used at Addenbrookes Hospital called "My Chart" where a patient can question something on their record for the clinician to check. Attendees said that anonymised data could also be used to:

- provide **more targeted information which is personalised to the individual** e.g., how to discuss a diagnosis with young children or provide information for a young person living with cancer.
- provide **improved statistics,** as patients are often told these are out -of-date so not to look for, or rely on them, creating an opportunity for Imperial to become the **credible source** of this information in the future. However, it is vital that patients and healthcare professionals can access the updated data and statistics and that the information can be provided in '**real-time'** and be accessible.
- **provide education and raise awareness** of ovarian cancer for both healthcare professionals, patients, and the wider public. This was considered particularly important for GPs to **improve early, timely diagnosis** e.g., ordering a **CA125 test** routinely, understanding **common misdiagnoses** of ovarian cancer, reducing delays in getting a GP appointment for symptoms which could be linked to ovarian cancer. "*Some GPs have been slow to make a diagnosis in rare cases of ovarian cancer occurring in BRCA patients who had previously had healthy ovaries removed as a preventative measure. Greater awareness of ovarian cancer signs and symptoms is much needed amongst healthcare professionals in, for example, less academic settings.*"
- identify and share **"success stories"** relating to **quality of life and access to trials** to give other patients hope and to inform healthcare professionals.
- **improve and extend prognosis timeframes** as currently the data "*stops at 5 years*".
- explore **wellbeing** and **psychological impacts beyond chemotherapy and initial treatment**
- explore the reasons for **inequalities of care**
- **disseminate available treatment options** to rural areas to **decrease inequalities in care**
- improve care by widely **disseminating key insights** from the data to health professionals, patients, and the public**.** However, it was queried whether the data would need to be published, analysed and peer reviewed before it would change practice.

The following were suggested as additional data sources (if these were not already being used):

- **clinical trial patient reported outcomes** and **quality of life measures** collected on paper (or by an app) which should also include a free text option. This trial data (including those in trial control groups) could be useful to explore **long term impacts and outcomes**.
- **patient reported side effects.** Attendees expressed support for **recording their chemotherapy side effects themselves digitally** in real-time
- **patient experience information** including how people have "coped with treatment" as this can impact treatment outcomes
- **link and use primary care data to improve diagnosis and reduce misdiagnosis** including referral data, time to diagnosis, medical history that might inform a cancer diagnosis and codings from GPs (who for example, may misdiagnose ovarian cancer as IBS)
- **lifestyle data** e.g., diet and nutrition, the impact of stress and how people live their lives
- **collect, use and combine genetic data** other than BRCA gene data, including data held in different hospital systems

We know that not all patients with ovarian cancer have access to equal care. These inequalities may affect the treatment given and overall outcome. **Can you think of reasons for these inequalities in care?** *What data could we look at to explore these inequalities?*

Attendees discussed what they considered to be the reasons for inequalities in care. Their responses centred around:

- the **ability to access: high quality care or second opinions; centres of excellence; and clinical trials** due to:
    - geography (referred to as a "postcode lottery")
    - socio- economic status including prohibitive costs of travel for patients and their partner/carer who may need to travel with them for support and the time needed off work/significant loss of wages
- **time to diagnosis** in terms of delay or misdiagnosis
- **awareness of research, treatments, and interventions available** due to differences in dissemination of this information across health services/centres and staff
- **differing advice** provided by oncologists as to treatment
- **inconsistent level of care**
- differences in the **quality of GP service** i.e., the ability to get appointments, discuss symptoms, obtain a referral, time to receive an accurate diagnosis and also for follow-up care post-treatment. Hesitancy by GPs to refer patients to undergo tests and scans and the consequential time wasted could mean diagnosis e.g., at Stage 4 instead of Stage 3. Communication between GPs and hospitals could contribute to inequalities in care. However, not all attendees had had negative experiences with their GP, with one saying their GP had recognised their symptoms immediately and they received a referral in 2 weeks, (although this was before the pandemic).

- o **fragmentation of data** across different hospitals and healthcare provider systems e.g., a patient needing to physically take printed health records from one healthcare facility to another because the systems don't "talk" to one another.
- o **education and awareness raising** of ovarian cancer and its symptoms for both healthcare professionals (including GPs and medical students) as well as **patients** and the **wider public**. It was noted there are no television ads about ovarian cancer although there are about breast cancer.
- o **good practice** should also be shared more readily by healthcare professionals including **internationally.** One attendee stated there are better outcomes for ovarian cancer in Europe and America.
- o those with **disabilities** especially people with learning disabilities who may experience inequality of access to healthcare in addition to a possible **lack of awareness of symptoms.**
- o **budgets in individual healthcare trusts and staffing levels**.
- o those who don't speak **English as their first language**
- o those who aren't confident at expressing themselves to their GP e.g., asking for a CA125 test or who are **unsure or less confident to ask further questions** of their clinician e.g., ask for clarification or about research studies or care at other centres.
- o those with a **long history of vague symptoms**
- o some patients may also find the **language used by some healthcare professionals** quite technical and difficult to understand

Attendees suggested the following data could be collected to explore these inequalities:

- o location, postcode
- o diagnosis (stage/route/survival rate)
- o age
- o ethnicity
- o literacy levels
- o side effects
- o GP referral information
- o time to diagnosis
- o genetic data as well as BRCA
- o misdiagnosis
- o rare cancers
- o socio economic data including loss of wages and costs to travel to healthcare appointments
- o barriers to participation in research studies that include financial/employment issues
- o disability status
- o research and treatment options (including international)
- o budgets in individual healthcare trusts and staffing levels

How do you think we could use/should have used (anonymised) data to improve <u>your</u> care?

   a) What information/statistics would you like to know about all patients with ovarian cancer to support you during your diagnosis and care?
   b) What information would you like to have access to about your own/loved one's cancer?
   c) How would these have helped you manage your condition?

Attendees' responses to how data could be used to improve attendees' care centred around the following themes:

Helping patients and health care professionals (including GPs) make **more informed (and personalised) decisions** around treatment options and pathways by:

   o providing **up-to-date information about clinical trials and treatment options in plain language.** One attendee considered that when it comes to clinical trials, you have to trust your oncologist unless you are a doctor or a researcher and referenced an American website called "Smart Patient" which has information about all clinical trials in the US *"and that gives me a little bit insight of what to expect and which treatment I can have and all my options."*
   o **providing access to positive interim findings**, e.g., into maintenance therapies.
   o timely amalgamation into patient data of information on **treatment developments and advances** so this can be utilised for those recently diagnosed
   o disseminating **all treatment options available** nationally as well as their outcomes
   o **providing survival rate data** to assist with choosing treatment options
   o providing information on **access to trials and/or targeted therapies**
   o **educating GPs** so they have enough knowledge about: diagnosis, (e.g., ordering a CA125 test); side effects of treatment (e.g., high blood pressure and the need to prescribe medication to address this in order for cancer treatment to be able to continue).
   o disseminating the **many chemotherapy options**

Providing attendees with an informed outlook on possible experiences (e.g. side effects, psychological impacts) and outcomes by:

   o providing data on **outcomes of other patients** (including those in similar situations) e.g., anonymised data on **side effects** of maintenance medication (such as fatigue)
   o **sharing experiences with others on the same treatment** including side effects, anxiety etc *"I would really to get in touch with people who are of the same medicine as me and see if I'm actually I'm experiencing the same thing".* It was queried whether the NHS can play a role in connecting people together to do this.
   o providing **case studies** of other patients' stories.
   o sharing **qualitative data** e.g., shared tips/ideas on enhancing quality of life after treatment. One attendee suggested patients could **record how they were doing after treatment**, including their psychological well-being.

Providing hope and support about diagnosis and treatment outcomes:

   o a number of attendees said they would have wanted **mortality, survival and life expectancy statistics** (including recent and localised) although some cautioned that

- these can be scary, and it was noted that such statistics should not be used without context
  - sharing **good practice** more often would help to "*give hope*"
  - reframing ovarian cancer as a **chronic illness** made one attendee feel more positive

- Enhancing patient access to, and management of, health records:
  - one attendee said the **"Patients Know Best"** website has meant appointment management is easier and travel can be planned in advance which is cheaper
  - one attendee said they would like to **see all test reports** without having to ask for them

- Providing access to psychological, mental health and peer support to improve wellbeing:
  - having **peer-to-peer support** was identified as very helpful and encouraging by one attendee (which was provided by another patient further ahead of her in the treatment process).
  - information on the impact on one's **emotional mental health** and information to help **optimise well-being** "*in order to be more receptive to and get through treatment in the best way possible*" e.g., whether certain diets were useful for chemotherapy treatment i.e., keto or fasting
  - one attendee would have liked **psychological support** for which she didn't think to ask

- Specific areas on which attendees wanted more information were:
  - **BRCA**
  - chemotherapy induced **neuropathy**
  - **prehab** for surgery
  - information on **side effects** "*having data so you can be reassured that at each stage of treatment that it's going to be limited and potentially and more likely, and it's not going to it's not going to last forever*".
  - data collection for less standard things like **rare cancers**
  - **chemotherapy** including how the immune system can impact outcomes, information on the **incidence of missed chemotherapy sessions** because of 'bad' blood results and whether some people are more likely to respond well or not to chemotherapy
  - more guidance about how to manage their condition **after surgery**
  - **the impact of co-morbidities** and outcomes of others with the same co-morbidities "*when I was going through treatment, it would be useful for me to know that that was quite common, and not to, in the sense of worry too much about having that or statistics and knowledge about other issues that are linked with the treatment*"
  - **waiting times** could be better communicated with a phone number to call

One attendee commented that she had been provided with **sufficient information.**

Appendix 1: Demographics of attendees

Table 1: Demographic characteristics provided during event registration for discussion group (N=19/19)

Characteristics	n (%)
Age (in years)	
Mean (range)	52 (34-75)
Age groups (in years)	
18-24	0 (0.0)
25-34	1 (5.3)
35-44	0 (0.0)
45-54	6 (31.6)
55-64	5 (26.3)
65 – 74	4 (21.0)
75+	1 (5.3)
Prefer not to say	2 (10.5)
Gender	
Female	19 (100)
Male	0 (0.0)
Prefer not to say	0 (0.0)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	12 (63.2)
Irish	1 (5.3)
Gypsy or Irish Traveller	0 (0.0)
Other White background	2 (10.5)
Mixed/Multiple Ethnicity	
White and Black African	0 (0.0)
White and Black Caribbean	0 (0.0)
White and Asian	0 (0.0)
Other Mixed/Multiple background	1 (5.3)
Asian/Asian British	
Indian	1 (5.3)
Pakistani	0 (0.0)
Bangladeshi	0 (0.0)
Chinese	0 (0.0)
Other Asian background	0 (0.0)
Black/African/Caribbean/Black British	0 (0.0)
African	0 (0.0)
Caribbean	0 (0.0)
Other Black/African/Caribbean background	0 (0.0)
Other	

Arab	1 (5.3)
Any other ethnic group: "I am méditerranéen. Originally from the Lebanon".	1 (5.3)
Prefer not to say	0 (0.0)

Attendees from across England attended the session

County	Attendees
Greater London	10
West Yorkshire	1
Hampshire	1
West Yorkshire	1
Lancashire	1
Cambridgeshire	1
County Durham	1
Devon	1

Attendees' geographical location
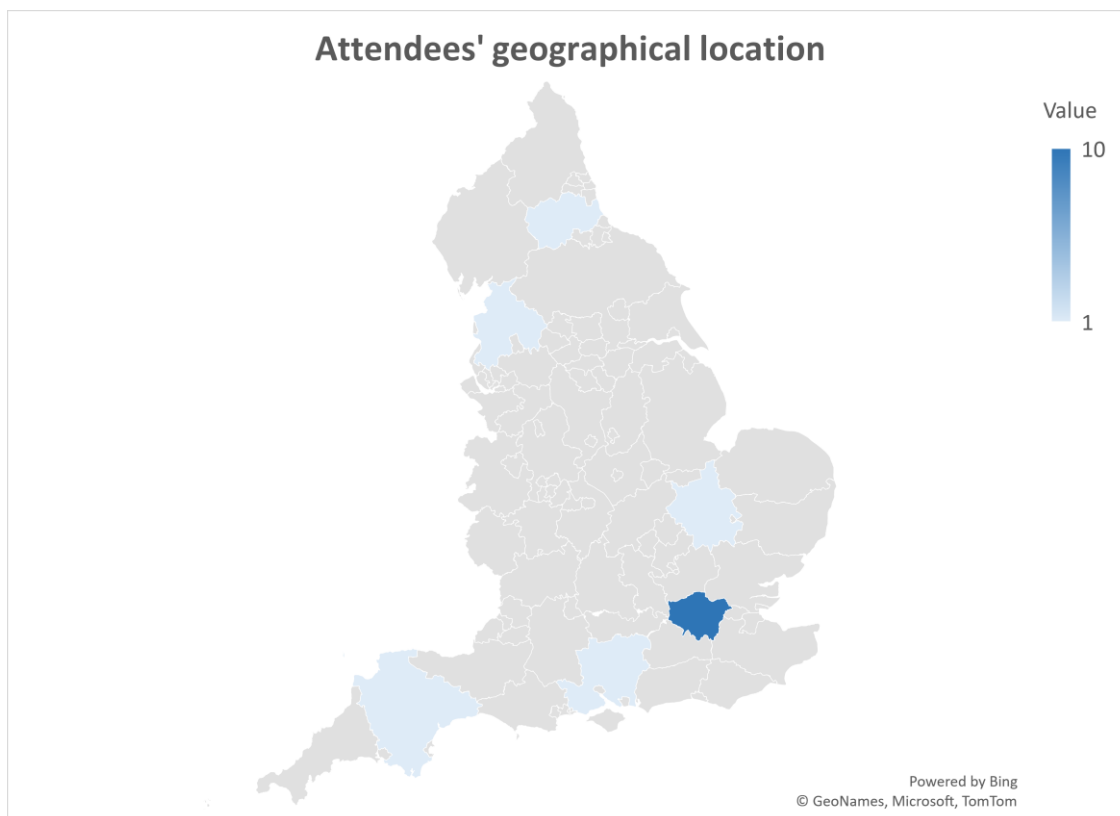
Appendix 2: Questions asked by attendees during the session

Questions asked and answered during the introductory session are set out below:

Q: Are other centres doing something similar?

A: We have already reached out to other centres to help with a collaboration to try and make sure that we've got information across the country and other centres are starting to do similar things. There's a collaborative called the Health Informatics Collaborative (HIC) that is trying to do exactly this, combining data together across centres. What we hope to do with this project is firstly show that NHS level data can answer complex questions about ovarian cancer management so then we can share our learnings with other centres and then ultimately combine everything.

Q: You talked about the database data that already exists and you mentioned certain categories on which you're already collecting data. Is that a concrete list that you provided in the presentation or are there more subcategories?

A: There are more that we are collecting and we hope to develop it and it will evolve over time as new things are known. Once we've proved that the data can give us some useful information, then we want to make it automatic so it's being updated almost in real time and we can then display updated data to everyone that needs it.

Q: What would you do if you had two patients with the same year of birth or even the same month of birth because a friend and myself were both at the same GP and have the same date of birth except a different year. So how would you get around that?

A: In terms of the clinical side of things, there wouldn't be a concern because the clinician who would be treating you would use other information as well e.g., your address, your name, your NHS number, your hospital number. We identify patients using a unique identifier which is usually a study ID number that says these data relate to patient number 123456 and they would use that unique identifier to match information within a record, but they wouldn't have any way of relating that particular identifier back to an individual.

Q: When you gather that data, do you separate the patients by, say ovarian cancer stage four, or stage two? Does it make a difference for your data, or in general? Because a patient's stage two experience is completely different from one stage experience.

A: You're absolutely right. This is one of the key things that we need to look at and collecting that key data on diagnosis. Things like stage is key and we know that and we need to know that for the data and for analysing the data. What stage and what the cell type is will be collected because we know that this guides treatment and guides everything else so we're collecting very specific data on patients' cancers.

Q: Will you have you been including things like how people react to side effects of chemo and treatment?

A: It's quite complex but yes, ultimately, that is definitely something we can look at. We will certainly be looking at data we have on what chemotherapy, what the treatment is and when it's given. So we will see if there's any dose changes or anything else. And then the next thing to look at is people's experience of that treatment but that will be our next step to really understand that.

Q: I think Ben was saying that the geographical area with postcode is left out of the data but is that not really important in terms of if you've got one area of the country that's got a huge number of Stage Four diagnoses coming through? But you've got say I don't know Imperial, or in London where a lot of the diagnoses are stage two and are caught much earlier. That's surely really important data that you need to be able to look at.

A: The full postcode is left out of the data because your full postcode can identify back to a very specific area, and that can be between one and 100 people, or one and 100 households. Going into that level of detail isn't something that we want to do unless we have specific causes to do so. If we were going to be doing that as part of research, we want to make sure that we have appropriate approvals to use that information. We will use the postcode, for example, to generate a deprivation score which may tell us a bit about the area someone lives in, or we have a team of people who work in the College doing work on small area statistics where they will provide other bits of information about that particular area which will allow us to understand what was going on there rather than where it was. What we also do is use aggregate postcodes, say the first three digits or first section will cover a population of several thousand people so we use that location information appropriately. We do have to be very careful about how we use that because it could be identifiable and what we don't want to do is use any identifiable information.

Q: Is there any way of you looking at of being able to gain data from epi genetics, that affect long term prognosis?

A: We spent lots of time talking about genetic mutations. The data we can collect is the data that we have on our system so we are collecting genetic data because it is very key in ovarian cancer as we move forward.

Q: the whole postcode thing, because it's so important. If you do take the point if there's a huge bulge somewhere, we really need to know if it's only bad diagnosis by GP. Is that digging too far down?

A: So we will know referral patterns So and you're absolutely correct. We know there is geographical differences and we do need to address it. We will pull part of it, but to the level of detail that Ben talked about, for all those reasons.

Appendix 3: Questions asked by attendees during break out room one

Questions asked and answered during break out room one:

Q: The written patient surveys that we do as part of my interaction with the clinical trial coordinator that ask how you're feeling at any point, e.g., whether you have nausea, sickness, what happens to all that data and how does that get used if at all? We never see the results although I got the feeling that it was used to improve my personal care, which is great for me however it seems to me that that could have much wider use that if you find a general issue or something that is affecting everybody. Is that ever being picked up through that?

A: It is usually used to adjust treatment that you're having so it's used for making sure we're not giving too much and causing more problems than benefits in the treatment. You seem to be suggesting that storing this kind of data and maybe aggregating it and seeing what the trends are could be useful. At the moment, it's just used for your care as a snapshot and they're not stored and that could partly be resources. It also could be that we haven't thought of it and it's definitely something that we'll take a look into.

Q: Did you encounter any person who is sick at the hospital who said I don't want to fill any data?

A: No, maybe there's an implicit understanding that it's important for their care, or it's important that we track this kind of information. So the majority of people are happy to participate in studies where we have to fill out this kind of data.

Appendix 4: Questions asked by attendees during break out room two

Questions asked and answered during break out room two:

Q: You mentioned the data is on different separate servers. Are you going to extract the data individually, or make them shake hands and build them centrally for data analysis?

A: So within many NHS systems, it depends what electronic system you're using, but certainly within the system, you have a system for patient records. You may have a system for chemotherapy prescribing, which is a separate one. You may have a system where you get all your genetic results on a separate system. Clearly, that needs work. That is a big NHS digital project and the system that we use at Imperial is actually different to the system that they use in Cambridge, for example. It's different to the system that they use at UCH but that, unfortunately, is something that we alone cannot address.

Q: I'm asking this in relation to the postcode which could be overcome by coding the postcode when the data is coded if it is transferred

A: What we are doing as part of this project is 'sucking the data' from the systems that we use e.g., take the data from patient records where we've got for example the blood results, take the data from the pathology system, which is a different system, take it directly from there and take the data from the chemotherapy prescribing system. So we know all of that and then join it together, combine it to make it useful, and then feed that back.

Q: Is there data cleansing as well after that?

A: There has to be lots of data cleansing because we have to make sure the data is only as good as the data that is inputted either by clinicians or whoever. So it's a key part and then ultimately we say this is our package from Imperial and then we want to get data (in the future) from other centres which will all be housed in a very safe data warehouse and we will use that data moving forward, starting this project at Imperial first, and then moving out from that

Q: Is it worth giving a quick explanation of data cleansing just for people who might not know

A: Data cleansing is when we essentially ask the question 'is the data answering the questions that we think it's answering?' so how good is the data, making sure that it has captured everybody with ovarian cancer because that's the first key to make sure that we are filtering those results and capturing it properly and making sure that the data is correct. What we would like to try and do is every so often display a checkbox saying the data shows that your patient has had surgery, then chemotherapy, for example, is this correct? Yes or no? To make sure that this is accurate data and that that's part of what the IT team are going to work on i.e. how can we make sure the data we have is always correct

Q: Do we think that this particular project could potentially enhance primary care going forward?

A: Ultimately, yes, looking back is also quite important and looking at referral patterns. We could start to look at the number of times you visited GPs, in the six months prior to diagnosis and it will probably lead on potentially to an education piece both for all healthcare professionals, and maybe actually we should be giving other health professionals more information regarding the treatment that we are delivering so, everyone is aware, e.g. you may have problems with blood counts or blood pressure or something like that.

Q: I'm checking back to the verification of the diagnosis list and you said there'd be a tick box that would come up. Would that be clinician verified or patient verified or a combination of both?

A: The way that the feedback is proposed to work and they've managed it with other sorts of pop up boxes, will be clinician verified. So this is what we think your patient has had that this data shows, are we correct?

## Appendix 5: Post- session feedback from attendees (n=13/19)

In the post-session anonymous feedback form emailed to attendees, they were asked practical questions about the session including how they rated it, their motivations for joining and which parts they liked the most. Please see below for further details. Respondents were also asked if they had any further responses to the questions posed in the breakout rooms and these responses have been consolidated with those provided in the breakout rooms above in the Key Insight Summary above.

Question 1: Is this the first time you have joined an Imperial College, London or Imperial College Healthcare NHS Trust event in person or online?
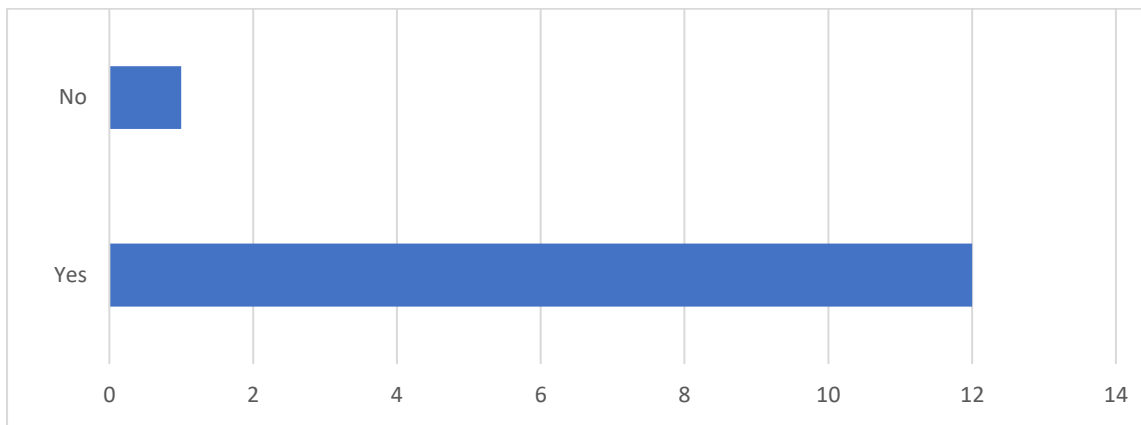
Yes	12
No	1

Question 2: How did you hear about this session?
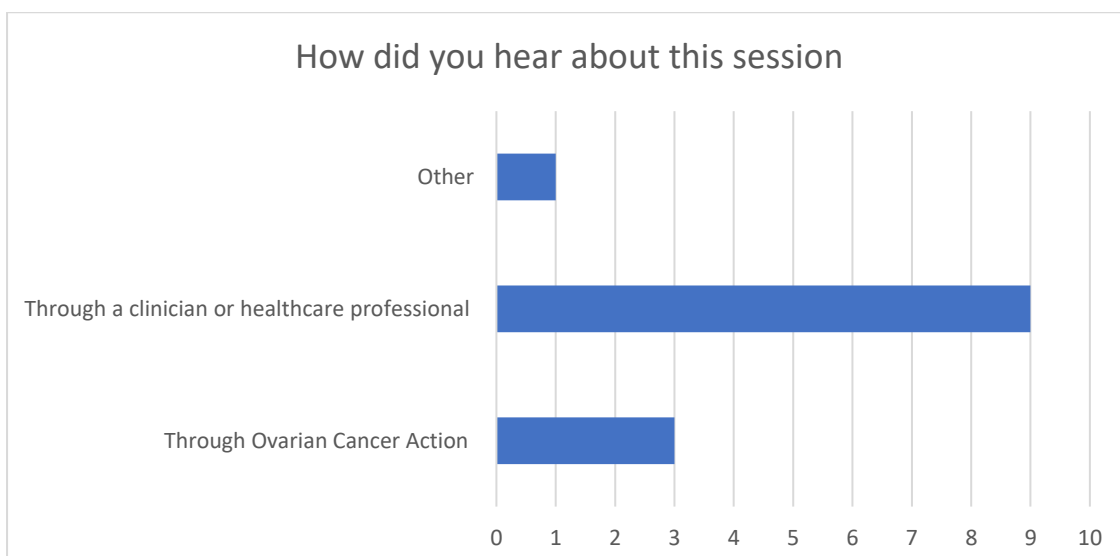
Through Ovarian Cancer Action	3	
Through a clinician or healthcare professional	9	
Other (please share)	1	Email from the clinical trial admin at Hammersmith Hospital

Question 3: On a scale of 1-5, how would you rate the session?
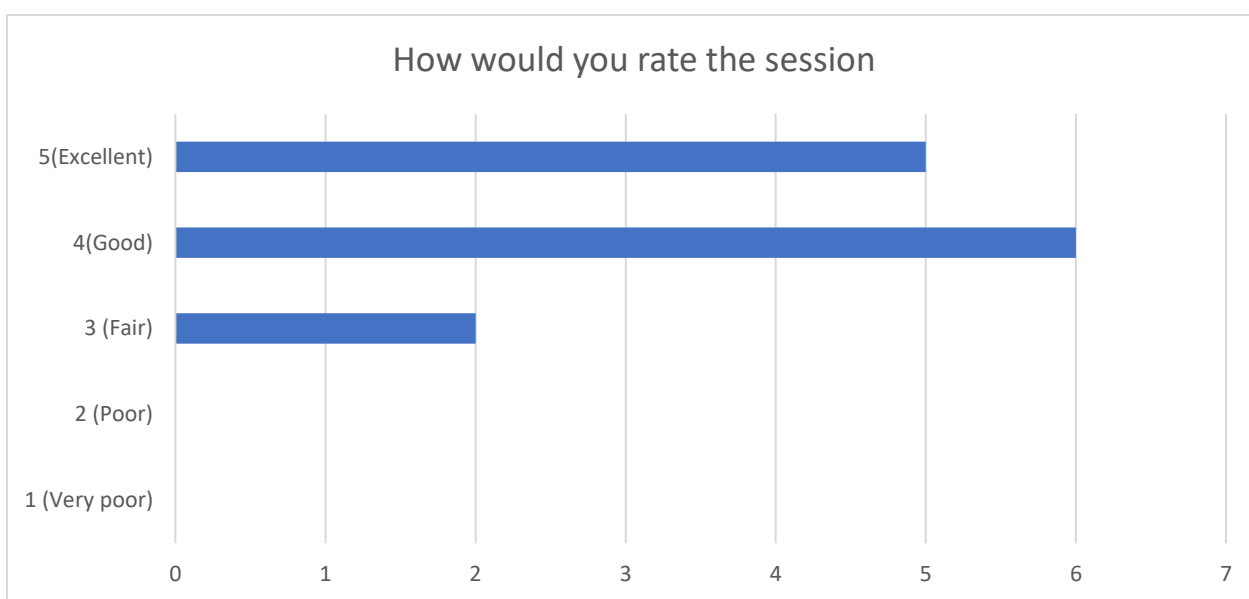
1 (Very Poor)	0
2 (Poor)	0
3 (Fair)	2
4 (Good)	6
5 (Excellent)	5

Question 4: What did you like most, if anything, about the session? Feel free to include the reason why in the free text box provided below.
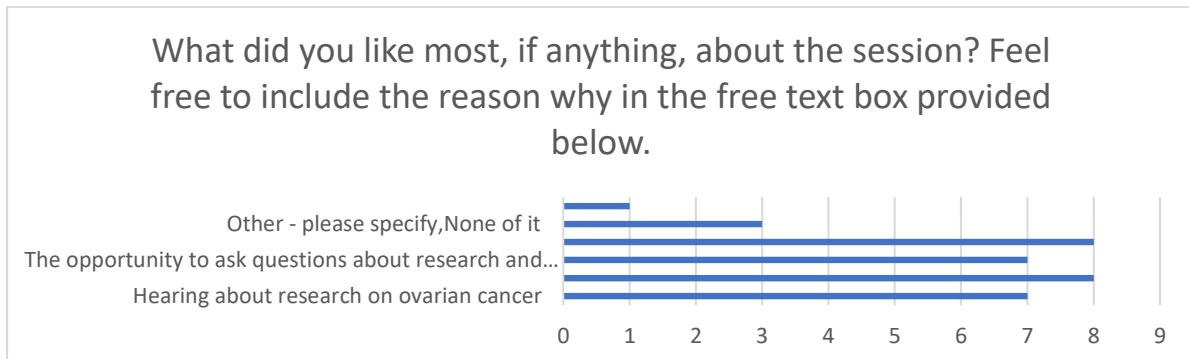
| Hearing about research on ovarian cancer	7
Hearing about the use of data in research	8
The opportunity to ask questions about research and hear answers	7
Taking part in smaller discussion sessions	8
Other - please specify (see below)	3
None of it	1

Free text - Other

- It is always useful to include patients as early as possible in research projects to get their views on what's important to them. I felt this was a very inclusive workshop and It was useful to have discussions in small groups. Thank you for organising!

- I found the whole session extremely informative, especially the proposed use of the data to identify trends in treatment and how these could affect future decisions.

- Interesting to find out how using data works

Reason why and any other comments:

It was a really useful forum to speak directly with clinicians and researchers and also to hear comments and questions from other ovarian cancer patients. The small group sessions were really useful too. I felt more confident raising points in a smaller discussion group.

Question 5: Please tell us your main motivations for attending the session? [Feel free to choose more than one]
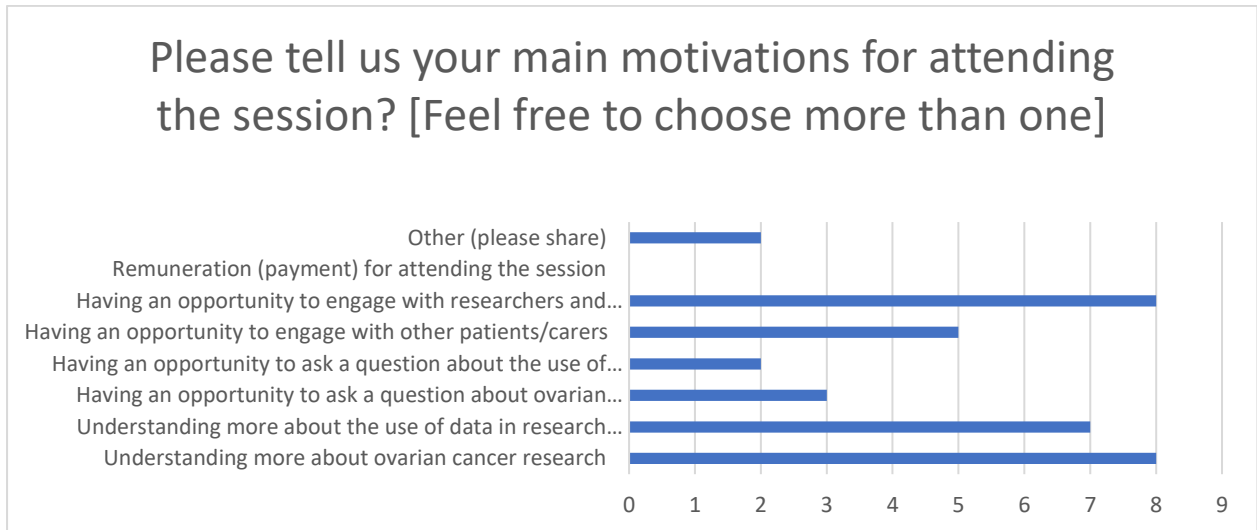
Understanding more about ovarian cancer research	8
Understanding more about the use of data in research generally	7
Having an opportunity to ask a question about ovarian cancer research	3
Having an opportunity to ask a question about the use of data in research	2
Having an opportunity to engage with other patients/carers	5
Having an opportunity to engage with researchers and clinicians at Imperial College, London and Imperial College Healthcare NHS Trust	8
Remuneration (payment) for attending the session	0
Other (please share) (see below)	2

Free text – other

- Make a contribution, if applicable

- Having an opportunity to contribute and share my own experiences to inform research

Question 6: In the breakout rooms you were asked the following questions. If you didn't get a chance to answer these at the time or would like to add anything else, please respond below.
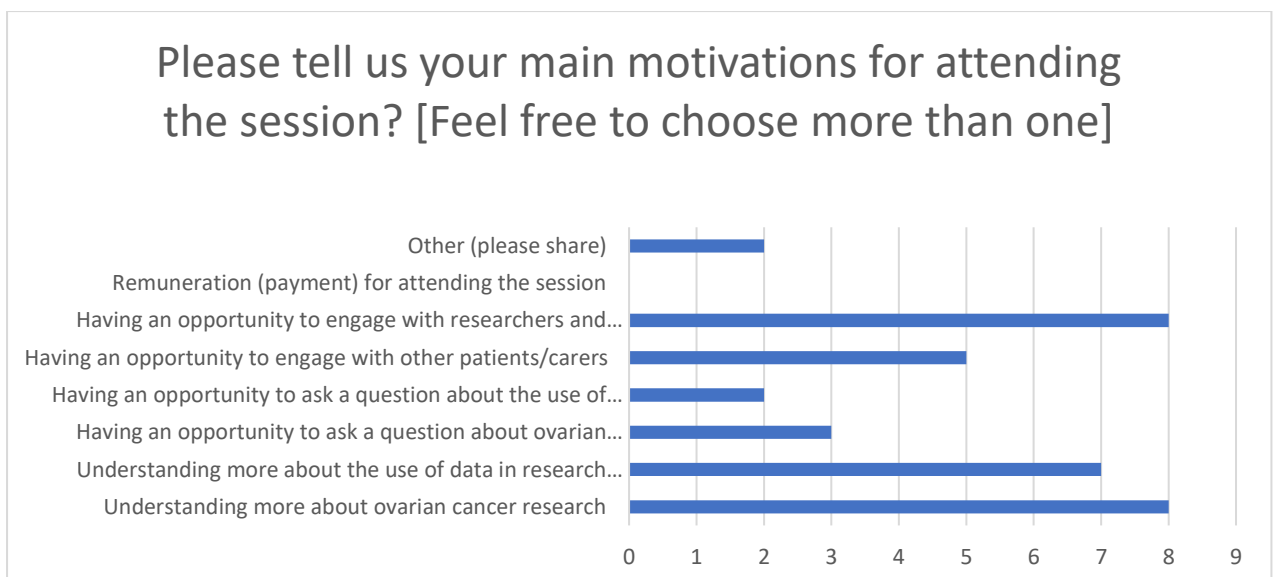
These responses have been included in the Key Insights Summary above

Question 7: How likely are you to attend a session helping to shape a research project again?

How likely are you to attend a session helping to shape a research project again?

Category	Value
Extremely	(bar to 6)
Very	(bar to 7)
Moderately	
Slightly	
Not at all	

(X-axis: 0 to 8)

Not at all	0
Slightly	0
Moderately	0
Very	7
Extremely	6

Question 8: Do you think you were provided with sufficient information about the session prior to attending?

Please tell us your main motivations for attending the session? [Feel free to choose more than one]

Category	Value
Other (please share)	(bar to 2)
Remuneration (payment) for attending the session	
Having an opportunity to engage with researchers and…	(bar to 8)
Having an opportunity to engage with other patients/carers	(bar to 5)
Having an opportunity to ask a question about the use of…	(bar to 2)
Having an opportunity to ask a question about ovarian…	(bar to 3)
Understanding more about the use of data in research…	(bar to 7)
Understanding more about ovarian cancer research	(bar to 8)

(X-axis: 0 to 9)

Yes	12	
No, please tell us how this could be improved	1	It would have been helpful to have more information about the project before the session and to be clearer about what was being asked of us as participants. I found the questions a little unclear without the context

Question 9: Do you have any further comments or thoughts on how we can improve these kinds of sessions?

- Not sure. I hate Zoom, but obviously you can include a wider range of people from all over the country.
- n/a
- The session was well organised and the presenters were very considerate of those people contributing. However, I would be interested to know whether any changes are made to the research based on the women's contributions.
- Keep doing them please. They're useful.
- No, I thought the balance of whole group and breakout room sessions was excellent, especially the amount of time allowed for the small group discussion. Whole 90 minute Zoom meeting was well structured and managed very smoothly and efficiently and it was a privilege to be involved. Thank you for giving me the opportunity to attend and contribute to this fascinating session.
- thought the contents etc was just right
- Thank you for your efforts improving care of patients with ovarian cancer
- It might be useful to hear Clinicians speak more about their work and their aims, as this appeared interesting.