



Healthcare data in research. What can you see? Public Involvement Workshop

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Dr Arlene Casey wanted to know what conditions and symptoms older adults commonly associated with later life. She was also keen to explore how members of the public viewed using unstructured medical data, such as the handwritten notes in medical files, in health research. Alongside colleagues from [DataLoch](#), Arlene approached the ACRC Public Involvement Co-ordinator, Jenny Robertson, to discuss how we could explore these topics with members of the public. We decided to hold an in-person workshop to stimulate in-depth discussion at a venue in central Edinburgh.

The event was attended by seven members of the [ACRC Public Involvement Network](#) and [AIM-CISC Public Reference Group](#) who were interested in research into long-term conditions and the use of healthcare data in research.

Three topics were discussed over the course of the day:

1. Common and important health related problems in older age
2. Medications and serious side effects
3. Healthcare data in research

Each topic was introduced by a researcher and was followed by a table discussion.

Session 1 - Geriatric Syndromes (Arlene Casey)

The first part of the workshop focused on common and important health related problems in older age, which are commonly referred to in the medical field as 'geriatric syndromes'. Workshop attendees were given a short introduction to working with patient health data, in particular clinical free-text and why working with this data is beneficial e.g. allowing for a better understanding and insight into conditions and problems in older age. They were also shown an example text where information was labelled from the reports and explained that health data workers use this to develop algorithms that can mimic problem-solving and decision-making capabilities of medical professionals. We explained to do this well researchers need to understand what common ailments matter the most and ensure patient priorities were embedded in the research. The groups were asked to discuss two questions:

- 1) What health-related problems did they think were common and important in older age?
- 2) Did they have any alternatives to the term geriatric syndromes?

Common symptoms in older age

During the discussion the most common conditions mentioned were:

| Diabetes | Arthritis | Fatigue | Dementia |
|------------------------|--|---|-----------------------------------|
| Blood pressure | Visual impairment | Continence issues (both urinary and bowel) – particularly in relation to access to public toilets which can limit daily activities and social life. | Having a suppressed immune system |
| Chronic pain | Frailty and lack of mobility and balance | Mental health including emotional support needed for carers | Isolation, grief, and loneliness |
| Anxiety and depression | Stress | Menopause/male equivalent | Caring responsibilities |

Pain was a new and surprising symptom that we hadn't previously considered as a common symptom in older age, as was menopausal/male equivalent type concerns. Pain was mentioned as becoming normal in older age, as was having to take pain killers.

There was some discussion on how Covid has possibly altered the landscape of common problems in later life, such as by impacting levels of anxiety, loneliness, social related problems, and access to care.

It was highlighted early in the conversations that people's health is affected in different ways and that the conditions of importance would differ between sub-populations e.g. in ethnic minority groups. It was also mentioned that some people would not view these chronic conditions necessarily as illness but as an inevitable part of ageing that cannot be avoided or prevented.

Access to Healthcare and communication

There was a lot of discussion around access to GP/healthcare services and it was of concern that the methods of communication such as telephone consultations or text messages were not suitable for an ageing population with hearing and visual impairments. One attendee said that he perceived a cut off of 70-80yrs of age, after which people found it hard to use technology to engage in healthcare. Attendees emphasised the value of face-2-face appointments. A lack of continuity in healthcare was also mentioned, with attendees commenting that seeing different doctors is not good for older adults and especially people with multiple long term conditions. A common issue was the lack of communication between medical practitioners about conditions, leading to patients repeating themselves to multiple healthcare professionals and causing unnecessary delays and duplication of, for example, investigations. Attendees highlighted a need for a more person-focused approach from the system and data, so that services can see what is happening for a person in all of the services that they use and have all the information at their fingertips. An example of this is someone with immune-suppression where they must remind medical practitioners of this as it is not documented well in their records but has a big influence on their care and treatment.

There were questions on the visibility of the health-care system as a whole and how medical records were shared and communicated. There was curiosity about how GPs view records and what they see, and whether this could be improved.

Geriatric syndromes

The group were also asked to suggest possible alternatives for the term 'geriatric syndromes'. They suggested:

- Advanced Care
- Ageing in Vitality
- Coffin Dodging
- Ageing and vitality
- Advanced Age
- Degeneration of ageing
- Problems of ageing

Session 2 - The public's perception of adverse drug events (Imane Guellil)

Introduction

For this part, we were interested in the public's perception of adverse drug events (ADEs). This included what the attendees consider to be the most problematic ADEs and what level of side effect would make them decide to stop taking a medication. Following a short presentation on ADEs, we discussed the aforementioned questions in two groups.

The most problematic side-effects for people taking multiple medications

The attendees highlighted some general side effects including:

| | | | |
|---|--|---|--|
| Nausea (especially related to chemotherapy) | Insomnia/ Sleep disturbance | Pain (including pain in fingers) | High blood pressure related to some medicines for diabetes |
| Light-headedness | Feeling sleepy | Fatigue/ Extreme fatigue | Weight loss or weight gain with changes in appetite |
| Allergic reactions | Headache | Flatulence | Losing concentration or motivation/apathy |
| Visual problems | Neurological conditions such as 'brain zap' – flashing light when turning head | Anxiety was discussed both as a direct effect of taking medication and also in relation to polypharmacy | Dizziness |
| Stomach problems | | | |

Attendees also highlighted how severe the side effects of some drugs can be, such as drugs used to treat depression which can cause suicide.

However, attendees were more concerned about the social side-effects from medications including:

- Severe constipation
- Diarrhoea
- Dryness of mouth
- Nausea
- Injecting

There was also quite a lot of discussion about how to know that a symptom is a side effect of medication and not a symptom of a condition in itself, and particularly how a connection could be made using medical records/text, unless specifically stated in the written text. Attendees mentioned starting and stopping medications to 'test' what possible drug interactions or side effects they may be experiencing. Attendees also mentioned that some side effects of medications can be compounded when taking multiple medications together. Eg, many medications can cause constipation so when taking these medications together this becomes a major issue. The challenges of polypharmacy and the feeling of having to self-manage multiple conditions came up repeatedly throughout the day, and there was a general feeling that side-effects of medications is another anxiety that comes from living with long-term conditions.

The level of side effects leading people to stop taking a medication

Attendees highlighted that often it is not easy to stop taking medicines as they take time to wash out of the body and there can be severe side effects from stopping medications, especially suddenly. It can take months to come off some medications and attendees spoke about needing to think about both treatment and withdrawal side effects.

There was an overall feeling that if the medication significantly diminished quality of life to the point that the person would see a medical professional about it then they would consider stopping the medication—and, again, this level may be very personal and differ between different people and contexts.

However, there were very different opinions about whether attendees would seek medical advice before stopping a medication. Some attendees said that they would never stop a medication without seeking medical advice first whereas others would stop it themselves if they were concerned about it. This response was also influenced by the context of access to care, in that if it would take a very long time to get advice they may just stop/reduce the medication themselves. Also, it was mentioned that this decision may be influenced by advice from family members, and this may be particularly relevant for some ethnic minority communities. Lastly, attendees mentioned that people taking multiple medications may be more aware of and more concerned about side effects than those not taking many medications, and so they may, for example, be more likely to read medication information leaflets and consider possible interactions.

Other discussions

Treatment burden and the anxiety that this can cause was raised as an important issue, particularly for those who care for someone needing medications. People also felt

Session 3 – Free Text in Research

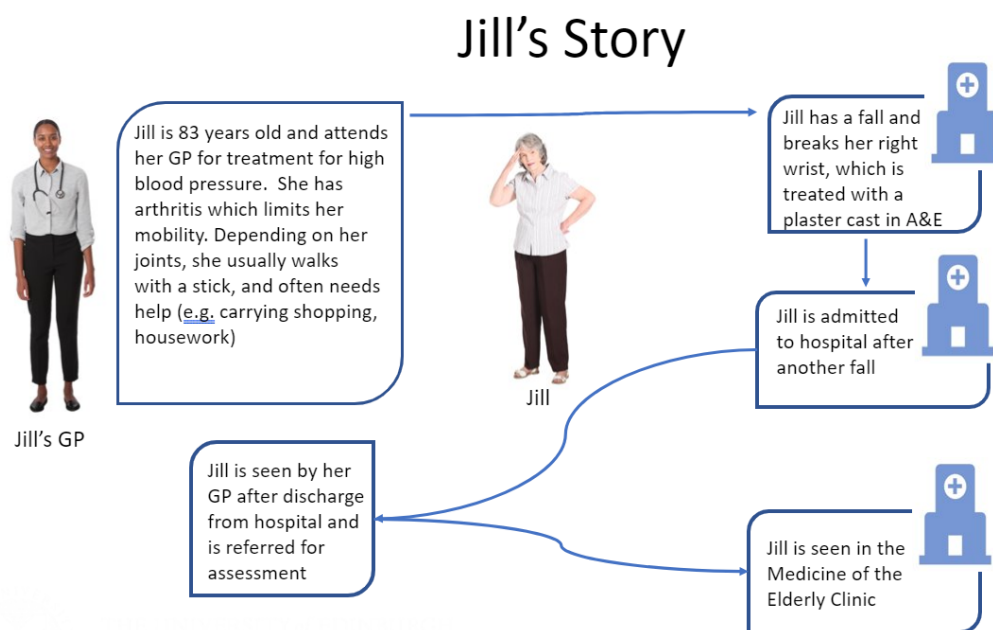
Introduction

Healthcare data is protected as a special category under Data Protection laws, and therefore must be treated carefully. However, healthcare records can contain information of varying sensitivity – knowing the number of appointments a person has attended may be seen as less privacy invasive than knowing their substance misuse history. The issues discussed in the final session of the day were focused on what unstructured information researchers using healthcare data should be able to access without compromising patient privacy.

that they were required to ‘be their own doctor’ when it came to managing medications and the challenges that this poses in terms of reading the medication leaflets to understand what could be a new side-effect and what is a new symptom.

The types of data held within healthcare records were described and separated into structured (or coded) data and unstructured (or free text) data. Participants also watched a short video from Clinical Lead for DataLoch Dr Atul Anand, describing how data services such as DataLoch keep data secure for research, including a requirement to minimise and de-identify the information given to researchers.

To bring the issue into focus, participants were presented with unstructured electronic health records (EHRs) from a fictional patient “Jill” during some of her interactions with the health system.



Information within the fictional unstructured reports included Jill's age, physical appearance, medicine use, symptoms and conditions, family/social support situation, living conditions, hospital procedures, behaviour while in hospital, mental health status, occupational/social history, and substance use history.

Participants were asked to discuss (with the controls in place in secure data services) - If these were your healthcare records:

- How would you feel about researchers securely accessing these types of records for further research?
- Is there any information that you would like removed?
- If researchers have access to multiple records per patient, does the build up of information change your opinion?

Discussions:

Questions 1&2 – feelings on the type of records/removal of information

On the whole attendees were happy for the information in the extracts to be shared with researchers.

Comments such as “all of this information is relevant” highlighted the need to build up a picture to help healthcare professionals to understand the underlying issues that an individual was experiencing.

Attendees felt that valuable information would be lost if data sources weren't linked as things would be taken out of context. Attendees said that they would be 'frustrated' if there was missing information about them that was relevant and would rather that there was more information in their health records rather than less. It was stated that there might be important associations to be found in large data that included 'sensitive' information e.g. the association of mental health conditions with certain family/social issues.

When asked whether some information may be considered more private or identifiable, specifics such as postcode were classed as too much detail, whereas as the general area was OK. However, some different views were expressed. One person mentioned their only concern was researcher's knowledge of where data was sampled from. For example, if the researcher was to know that data was all from one GP practice then they could possibly identify people from this. However, if the data was from a large number of people and the researchers didn't know that level of detail (e.g. GP practice) then it was felt to be acceptable. .

One participant remained concerned about including information about a patient's relatives, although with further discussion this seemed to be more because they thought this was a confusing (and irrelevant) detail for researchers rather than because of privacy issues.

One attendee felt that some patients may not want some data (e.g. people's alcohol history, their relationship with their family) to be included in research data extracts. However this was not because of it being identifiable but more because they feel it is personal/sensitive to them. Other participants felt that some mental health information may not be appropriate to disclose in all cases, but overall the

group acknowledged that this information could contribute to an understanding of the data and should be provided if the project was investigating mental health. Attendees also expressed that most information was fine to share as long as the researchers using it sign agreements of confidentiality and that data would not identify people.

Question 3 - Multiple linked data sources

In relation to the build-up of data when linking multiple sources (e.g. GP, Hospital, Accident and Emergency etc.), attendees were not concerned that this could increase the likelihood of identification and, on the contrary, they felt it was important that these data were linked so that researchers would get the whole picture of someone's health/situation for their research.

Subjectivity/data type/bias

Lastly, there was some discussion of the subjectivity of what's written in healthcare records and how patients may not agree with what's been written. One participant stated that if the medical practitioners included details in their records then they must've felt they were relevant to this person's healthcare and so taking anything out would lose valuable information and that the healthcare professionals judgement should be relied upon.

However there was some disagreement on this. Some attendees felt the reports should only contain factual, objective information, and felt it was important to be aware of who had provided the information. It was discussed that potentially people may feel differently about notes written by a doctor versus a nurse, physio, occupational therapist etc. This centred on the use of the word 'paranoid' within the case study and whether this was an actual diagnosis or someone's opinion of behaviour and, if the latter, how reliable this could be taken by a researcher. This opinion may be affected by the source of the notes e.g. ward round notes versus GP notes versus discharge summary. Participants were aware of potential biases of both people providing the reports and those interpreting them, and the potential for bias by removing information.

Feedback/Views of the Day

Participants gave immediate feedback on a paper questionnaire. All participants felt the day was informative, the group size and amount of detail was about right, and they were able to participate. Participants suggested the day brought to light new

issues and should serve as a starting point for wider engagement and discussion as each session could be a full day of discussion.

We'd like to take this opportunity to thank all participants for their contributions and enthusiasm.

Conclusion/Key Learnings

- There were a number of conditions associated with later life, including pain, that aren't currently considered to be Geriatric Syndromes
- The lack of communication between medical practitioners about conditions is a common frustration for people with multiple long-term conditions
- Side-effects from medications and managing multiple treatments can cause significant anxiety for patients
- In theory all information held within unstructured electronic health records could be shared with researchers, with associated controls such as agreements and de-identification.
- There was not a concern about the build-up of information from multiple sources about a single data subject.
- Some information, such as family details and mental health, were acknowledged to be more sensitive, or potentially identifiable and therefore need to be relevant to the research in question, rather than provided automatically.
- Researchers need to be aware of the information provided in context – i.e. where it has come from and who provided it, maintaining knowledge of potential biases in both the data and their understanding of it.
- As recommended by one participant, repeating a similar workshop with a wider group, or a group who may not be as open/engaged with health research, would be beneficial to see if these views are replicated.

What Next?

- The geriatric syndromes and adverse events findings are being fed back to ACRC to consider what elements are most beneficial to target research efforts to support advanced care.
- DataLoch, in conjunction with other Scottish Safe Havens are working together on what level of de-identification is required as a baseline, and what could be provided for relevant research. We are now planning further public engagement events specifically in relation to free text data research and algorithm development by researchers.