

Feedback from the Imperial BRC Public Advisory Panel on the Proposed Digital Health Theme plans: 16.02.21

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Background

On 16 February 2021, the proposed Digital Health Theme (Mr Erik Mayer and Ben Glampson) presented the use of algorithms in patient care to members of the Imperial BRC Public Advisory Panel (Panel) via an online Zoom meeting. The title of the presentation made to the meeting was “Patient and public perception and thoughts on how ‘algorithms’ can be used to improve patient care through Electronic Health Records.”

Session Structure

The structure of the session was as follows:

- Introduction by Theme researchers to the one of the proposed Theme’s main areas of research, explanation of an electronic record and an algorithm (and its application in healthcare) followed by a Zoom poll
- Q&A
- Panel members were then split into two breakout rooms in order that smaller group discussions could take place facilitated by one Theme clinician/ researcher and a public involvement facilitator. During the breakout rooms, Panel members were asked to answer the following questions:
 - *Which of the six potential algorithms functions should be a priority?*
 - *Imagine we used an algorithm within your electronic health record to determine your risk of heart disease or another illness. What implications may this have on you as a patient, would you have any concerns? What benefits might there be?*
 - *How should patients be involved with informatics projects in the BRC Theme?*

Payment

In accordance with NIHR payment guidance, Panel members were paid for their time in accordance with NIHR payment guidelines including a £5 contribution to Wi-Fi/data for accessing a virtual meeting.

Summary of Key Insights

The following is a summary of the themes identified in breakout room discussions, more details of which are set out below in **Appendix 2**.

A zoom poll identified that algorithms that **diagnose new conditions and algorithms that aid clinical decision-making** were considered to be most valuable and should be prioritized by the proposed Digital Health Theme. They both received equal numbers of votes i.e. 53% (n= 9/17). Please see **Appendix 1** for more details. Panel members identified that algorithms which had the **most immediate effect** on patients were a priority including identifying disease risk, diagnosing conditions, and aiding clinical decision making. However, they also considered it important that **algorithms need to be developed in a way that is meaningful and responsive to both clinicians and patients**.

When presented with a scenario about algorithms being used to determine risk of heart disease and the concerns and benefits of this, Panel members considered the **benefits** to include the assistance

algorithms provide to decision making which benefits the patient. They could also see **possible uses** for algorithms which included alerts for vaccinations and National Early Warning Scores. However, the following were considered as needing to be addressed: **transparency** about, and **accessibility** to, their data, **uncovering additional health issues and communicating this ethically** to the patient and the need for follow on support, **consent is required** to use the algorithm and some patients may wish to opt out of an algorithm being used in relation to them. Patients would still want **the medical professional to have discretion** to overrule an algorithm and there is **a need for a relationship with a medical professional** whom a patient trust.

Their concerns about algorithms being used to determine risk of heart disease or other conditions included the **limitations of algorithms** including how their accuracy is monitored, the **algorithm validity** including how comprehensive and accurate the patient record information is and the **generalisability of the data** used in the algorithm and whether it represent all members of the population,

Patient Involvement in Theme

In relation to how patients should be involved with informatics projects in the BRC Theme, panel members considered that **large and diverse groups** should be involved in inclusive ways, processes should be embedded for **feedback, language used should be public facing** including providing for languages other than English, and **algorithms should be co-designed with patients**. However **public trust** needs to be built about artificial intelligence.

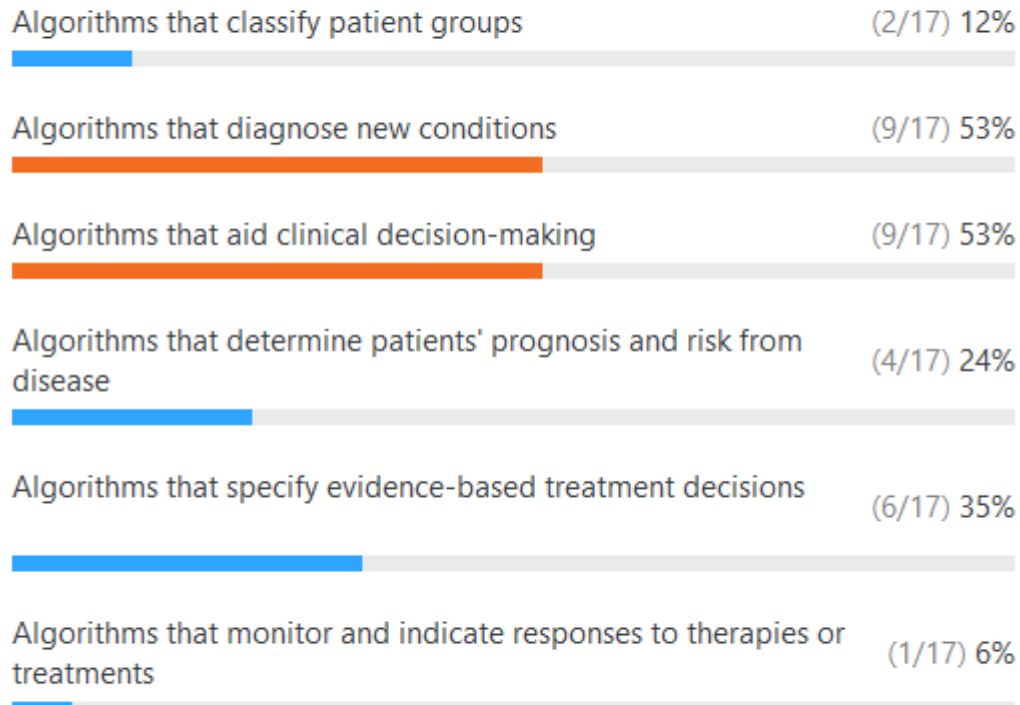
How we used the insights

This insight report summarising key points from the session was made available to Theme leads and the BRC Executive in order to shape the BRC application. The report was also provided to the Panel members who took part in the involvement activity. A full report on all public involvement activities undertaken in preparation for the BRC application can be found [here](#).

We would like to thank all those members of the public who gave their time and thoughtful insights through these activities, and the researchers who engaged enthusiastically in the process.

Appendix 1: Zoom poll results

1. Which of the below algorithm functions below do you think is most valuable and should be prioritised by the Informatics Team? (please choose your top 2) (Multiple choice)



Appendix 2: Breakout room discussions

Whilst in breakout rooms Panel members were asked to respond to three questions. The details of their responses are summarised in the relevant themes below.

1. Which of the six potential algorithms functions should be a priority?

The following comments (which have been themed) were made about the choices attendees made to the previous poll question:

Algorithms Functions with Immediate Effect

- Poll choice was based on what would have the most immediate effect on patients. Ensuring patients get the right sort of treatment, the right sort of management at the right time is the crucial thing.
- The 'classifying patient groups' and 'response to therapies' feel more like research priorities rather than potentially something that would have an immediate impact on the patient and their management.

Identify Risk of diseases

- One panel member felt the greatest benefit of such algorithms was to ensure that individuals' risk of certain diseases or outcomes could be predicted and measured and acted on at the earliest stage. This would have benefits for reducing hospital admissions etc.

Diagnostic and clinical decision-making

- I feel quite strongly that those kind of diagnostic clinical decision-making processes and risk calculation algorithms were priorities compared to the others, especially if they're just didn't used for research because I don't think we necessarily want to be put patients into groupings in that way anymore and may not be for the patients benefit.
- I feel I chose correctly initially, e.g. I still think 1 (classify patient groups) and 6 (monitor response to therapies) are for research and evaluation. 3 (clinical decision making) , 2 (diagnosis) and 5 (evidence-based treatment decisions) would be my priority.
- Creating ethical decision-making aids can be incredibly valuable to patients as they can ensure that clinicians have prompts at their fingertips relating to the most current clinical evidence – this would really help the patient get the most optimal treatment.

Patient and public involvement in algorithm development

- Hugely important area of healthcare. It needs a lot of thought and requires patients/public involved at all stages. The algorithm needs to be developed in a way that is meaningful both to clinicians and patients.
- Important that any algorithm is responsive to patients and the public. Reflecting on the Zoe App used during COVID-19 which highlighted that patients and the public felt there were symptoms outside of the current classification of COVID-19 symptoms which needed to be recognised. Need to also listen to their views about what symptoms are important when classifying patient groups.

2. Imagine we used an algorithm within your electronic health record to determine your risk of heart disease or another illness. What implications may this have on you as a patient, would you have any concerns? What benefits might there be?

The second question posed in the breakout rooms was a scenario i.e. “Imagine we used an algorithm within your electronic health record to determine your risk of heart disease or another illness. What implications may this have on you as a patient, would you have any concerns? What benefits might there be?” The following comments (which have been themed) were made about this scenario.

Benefits

- Everything that helps the clinical decision is a priority because at the end of the day, the patient needs to have the decision. Everything around the treatment should be a priority instead of “getting data for data”.
- I would definitely like to know what are my risks are from using my health data that you have and using the algorithm to determine my risk of heart disease or other illnesses.
- There are definitely many benefits to me of using algorithms.
- The benefits are huge with early, rapid, and accurate diagnosis.

Possible Uses of Algorithms

- It's a superb instrument for alerting all sorts of areas of the medical care system particularly for inoculations and various other things as well. For example, to recall, people, to put them further to the front of the queue for COVID, for example, it could be a very very useful tool.
- Will there be a use for that [algorithms] with the National Early Warning Scores, because at the moment, there is some controversy over it not working for people with particular ailments, and they're not flagged up as an emergency in hospitals. But perhaps in each patient's data in that AI algorithm system, it would perhaps save a lot of lives.

However the following aspects of using algorithms were identified as important:

Transparency and accessibility

- *Would I, as the patient, have a right to look at this data and agree whether the data is correct? People now want more transparency and want to know what is happening to their data*
- We need systems to which both clinicians and patients have access and control. We are re-commissioning Patient's Know Best Care Information Exchange with that in mind.
- The evidence base is so important, it is difficult for patients to access that and is currently a massive gap in patient care.
- More and more patients want to know that care and treatment has had individualised attention and how the evidence has been applied to them.
- People would be less hesitant of their data being used in this way if they know exactly what the consequences are of the use of the data that they are providing. They need to know the range of what the data tells you e.g. if this number goes over 10, this will be dangerous. They also may be concerned of being overtreated or over checked.

Ethical Considerations of findings

- We must remember ethical considerations too, if patient enters hospital for elective procedure and is advised then that they are at risk of imminent heart disease.
- It could alarm me further! Patients may require counselling if results are worse than anticipated.

- As long as there is no anxiety or stress generated and the patient does not feel spied it is important to be informed to act on the issue

Consent Required

- You require consent of the patient for using the algorithm. Although it's in their benefit, I think it's got to be clarified and they have got to agree to that.
- There is a point about consent and capacity. How would you get consent from an Alzheimer's patient? Do you involve the family or somebody who's responsible for the care?
- Do you not accept that that's just another form of personalised medical care and should be put to a patient as that because it's utilising aspects of a patients' records?
- I think everybody assumes that you (the doctor) are making the decision not algorithms. If my father were to go into the hospital he would say "the doctor told me so", he would not say that came from the algorithms. Therefore, I think there is an onus or responsibility from the healthcare professional (hospital) to provide this information.
- Are the patients aware that this is what you're doing i.e. that you are determining their risk or treatment, or care based on the algorithm?
- I would like to know how you came up with a risk assessment so it would be important for me to know if you're using the algorithm

Opting Out

- Do you envisage, people will request that an algorithm is not used, and there's a human check as well, as a double check or will you be saying to them, 'well we're trusting in the algorithm so we're just going to go with that'? At some point once we're more comfortable with using the algorithms there probably won't be requests to not use the algorithm, they'll be semi-automated, but they'll be ones that you can just run with it.

Need for medical professional discretion

- The ultimate decision is that of the consultant's, isn't it? You may look at the algorithm and all that, but would you override the algorithm, and say, 'No, this is what I want to do'?
- That would need to be made clear to the patient i.e. that the ultimate decision is that of the consultant? There could be a comforting factor for the patient to know that you (the doctor) know the person deciding.
- I feel it is a bit concerning and I fundamentally agree with what others have said about that it is the explanation that comes from the doctor that will be most important.

Need for medical professional relationship

- AI is very valuable to the patient, but the clinician who the patient understands and who can explain things to the patient is crucial.

Concerns

Panel members expressed the following concerns about the use of algorithms to determine risk of heart disease or another illness.

Limitations of Algorithms

- Normally patient concerns would be 'what if it goes wrong?' Is monitoring taking place person by person or are they monitoring, say, one every five people to ensure its correct?

- With a great deal of information being accumulated, does the algorithm occasionally get stuck or produce contradictory responses?

Concerns around algorithm validity.

- Being categorised into groups by a machine seems to not align with the move towards the aim of individualised care individualised medicine and may raise some red flags.
- Obviously, the accuracy of the algorithm will be hugely dependent on the amounts of information, and how comprehensive the patient record information is. Perhaps for example where a patient may have various allergies or an allergy to different medications or all sorts
- What about reassuring them (patients) about accuracy on medical records?
- The accuracy of the records is very, very important.

Generalisability

- What factors do you take into account in terms of being applicable for a diverse range of people e.g. race?
- Would you be comparing the algorithm with people who are potentially within the same category that I am in, or would you be just using my health record to determine that?

Views around remote monitoring and it's vision

- One attendee said they would not be in favour of remote monitoring for Alzheimer's for example because of privacy but if it's for the safety of the patient, then perhaps with family agreement that should be possible if the data is only looked at by the doctor. I think there's always a way, but it should be with the family authorisation.

3. How should patients be involved with informatics projects in the BRC Theme?

The third question posed in the breakout rooms was *"How should patients be involved with informatics projects in the BRC Theme?"*. The following comments (which have been themed) were made about this question.

Involve large and diverse groups

- Ensure that you are consulting a large and diverse group of people to really understand what the priority areas for algorithms are and the concerns of patients.
- Be inclusive

Embed processes for feedback

- Embed processes for feedback from patients and their carers.

Ensure language used is public facing

- It sounds as if “algorithm” is not so different from “programme” which I think is a term the public would more readily understand.
- When you are engaging/involving public members about this work, you need to show the algorithms in a patient-facing way rather than the benefits to clinicians. Remember the patient side of things at all times.

Co-design algorithms with patients

- There should be shared power over such algorithms between clinicians and patients
- Patients should be involved throughout and asked their thoughts on use of algorithms when used to diagnose risk etc.
- Through a supportive programme with full agreement
- By having a wide range of people in your steering group or focus group throughout the research project e.g. different demographics. So, if you're using this algorithm in a wide range of different areas and not just for heart disease so how would you get input from those different groups affected by diagnosis using an algorithm. Would you be able to engage a wide number?

Build public trust

- Public trust in AI will need to be built.

Appendix 1: Poll

A Zoom poll was undertaken during the main session asking the following question: “Which of the six potential algorithms functions should be a priority?” Algorithms that diagnose new conditions and algorithms that aid clinical decision-making both received equal numbers of votes (53% (n= 9/17)).

1. Which of the below algorithm functions below do you think is most valuable and should be prioritised by the Informatics Team? (please choose your top 2) (Multiple choice)

