

Consultation 1: FISH to Fusion

Should we be informing someone else when we start the change process?

You began by discussing what level of information patients and the public would need to know about a technical change, and what effect knowing would have on the patient. As members of the public you felt that it was important for people to trust in the scientific community. If the reasoning for why certain decisions are made is not clearly articulated, this can impact negatively on public trust. You gave the examples of the impact of false positive and false negative results on patient care, and the lack of clarity around antigen/antibody tests for COVID-19, as areas where there is confusion for the public. Information should come only from reputable sources and should be conveyed in lay terms. For example, Cancer Research UK is regarded as accomplished in conveying sometimes complex information to the interested public. It is also important to get the timing right; publishing something too early could lead to lessened impact when there is something significant to report.

What information would be most useful? What information should be shared? (by us and by you)

You again stressed the importance of understanding what value or impact the information would have on the patient, to determine whether or not disclosure would be useful. What impact would the change have on, for instance, turnaround times or accuracy of the test; longer wait times for a test result can have negative psychological impact on the patient. High quality information around a change in lab processes can help to reassure the patient that the right treatment plan is in place, improving their outcomes through personalized care pathways. You recognised that the amount of information to be provided around any incidental findings was personal to each patient and may depend on whether the information would have an impact on their ongoing care package. Some patients would choose not to know, whilst others would want to know all details, and as a result there needs to be a mechanism for managing this. The level of information a patient wants may also change over time, therefore the ability to provide a method for future contact with the service would be critical to ensure continuity in approach.

What information would be useful? What impact would this have on a) the laboratory and b) the patient and the public?

You again emphasized the importance of being patient-led and focusing information on the impact on treatment options for patients. What value would be added by knowing? Would the new test improve accuracy? You felt that the particular change described here would have a positive impact on the lab through long term cost savings resulting from fewer individual tests being required, and also reduce the patient test odyssey. You agreed that information given to patients and the public should be proportionate and measured, avoiding levels of detail that could cause confusion. If people wanted more information you believed having more detailed resources available on request would be beneficial. Expectations should be managed; for instance quicker test results may not necessarily lead to a quicker appointment with a consultant. Having the patient sample information stored as raw sequence data was seen as advantageous as it would reduce the need for resampling that may be required at a later date; the data could be reanalyzed as required.

Consultation 2: Pathogen Genomics

What would you like to know about an outbreak you are involved with, or outbreaks that occur (as a member of the public)?

You felt the initial public health statement at the start of an outbreak should be reassuring. From the COVID-19 pandemic response you highlighted that there needs to be a standardized system for getting results back to patients and that information should be freely available to those who want it. In the aftermath, a full evaluation of the response should take place to ensure lessons are learnt.

What would you like to know about a positive result during an outbreak?

You stated that it was important to identify, through contact tracing, when and where you likely contracted the virus, and how many other people are likely to be involved. You believed strongly that counselling should be available to wider family members as required, in addition to the person with a positive result. Resultant immunity following infection (specifically in the case of COVID-19 antibody testing) was an area of great interest.

Do you have an annual flu vaccination and, if so, what are your reasons behind your decision? Will the current Covid-19 pandemic influence your attitude towards flu vaccinations?

You were in favour of annual flu vaccinations, although you identified some barriers to uptake, such as a variance in public perception of risks of vaccination and a wariness around delivery. You believed drive-through and other 'no contact' vaccination sites might increase uptake. You expressed concern that people might not see the point in vaccination if uptake is poor. To combat this, clear and concise public information should be available to encourage participation in vaccination programmes as part of an individual's social responsibility. A public awareness campaign would help promote in a positive light.

How do you feel about your sample being sent to England instead of being processed in Wales?

You expressed the opinion that it should not matter where your sample is sent, if it is the most appropriate lab for analysing your results. However, you did feel that your results should be readily available in Wales, regardless of where the test is sent, and there were concerns that this has not happened with some tests sent to English labs. Processes, quality and policies need to be consistent across the UK to ensure sample results and data protection. Emphasis on more localised clusters, if a centralised approach to testing causes issues with local information and subsequent necessary action. Impact of loss of expertise in Wales on the economy was also raised and discussed.

How would you feel about your sample being processed in a commercial lab, rather than in the NHS?

You preferred that testing should be carried out/processed in an NHS lab but were keen not to see redundant labs (post-COVID-19 for example) so the use of a commercial lab may provide more flexibility in the short term. All data gathered by such commercial companies should be made available to clinicians responsible for managing local outbreak information. You stated that you would be happy to wait longer for a better, more accurate result.

Your Feedback

Thank you to all who have responded with feedback about this event; we have collated it to inform our future consultation planning. Overall you felt listened to at the meeting, and you felt comfortable sharing your thoughts and ideas, although some were nervous about feeding back on the virtual platform. You all felt you learnt something new, and that the event met your expectations and was beneficial and worthwhile.

Overall you were satisfied with the format, content and pace of the event. Some found it tiring, whereas others found it easier to attend and were more confident in expressing themselves than in face to face meetings.

Your experience of the reliability of technology differed with some indicating it went well, whilst others had technical problems. You also felt that Zoom, whilst a useful tool, was not very good for broader networking and getting to know each other.

On the whole you were satisfied with the format of the day and the quality in which complex information was presented. You gave the following suggestions for future events:

- Lunch break– your suggestions included using lunch breaks for structured ‘get to know you’ sessions and shortening them to facilitate an earlier finish time
- Improving technological reliability where practicably possible to ensure fewer dropouts and maximum engagement
- Continue to provide virtual connectivity when face to face meetings resume to include those who may struggle to attend meetings in person
- Provision of questions for breakout discussions prior to future meeting would be useful to allow preparation in advance

You made the following suggestions for future consultations:

- Monitoring and evaluation of the strategy
- Genetic engineering
- Raising the profile of the Partnership

There was a query about how the Sounding Board is funded (e.g. honorarium payment) and whether there is an impact on money provided for services. We would like to confirm that co-production is a specific funding stream provided by Welsh Government as part of the Strategy delivery budget and does not impact on the funds provided for genomic services.