

Meeting with the PFAS Scientific Advisory Panel

Wednesday 11 October 2023, 5:30pm to 7:30pm at Les Ormes

Minutes

Attendees

Members of the public were joined by:

PFAS Scientific Advisory Panel members:

- Dr Steve Hajioff, Independent PFAS Scientific Advisory Panel Chair
- Dr Tony Fletcher, PFAS and Health member
- Professor Ian Cousins, PFAS and Environment member

Along with Government officers: Professor Peter Bradley, Director of Public Health and Medical Officer for Health (joined online), Grace Norman, Deputy Director of Public Health, Dr Tim du Feu, Head of Land Resource Management, plus support staff.

Meeting notes

Welcome and Introduction

Handouts were made available in the meeting including copies of the latest PFAS newsletter, agenda for the next meeting of the Scientific Advisory Panel meeting on 12 October and the draft report and information slides referenced in the meeting. Documents are available online at [PFAS in Jersey \(gov.je\)](https://www.pfas.gov.je).

Grace Norman gave an introduction and explained that Ministers are aware of the meeting and have been updated on progress, however, they were not invited to this meeting to give Islanders the opportunity to speak directly with the PFAS Panel. Ministers will meet with Islanders later after they have considered report 1 to inform Islanders of how they will respond to the first report.

Grace Norman outlined the purpose of the meeting which was: an opportunity for Islanders to meet the Panel; To present the draft report 1 (The potential for an interim therapeutic phlebotomy service); To share the draft scope of report 2 (An assessment of the impact of PFAS exposure on health) and an opportunity for Islanders questions and to give their input.

Dr Steve Hajioff, Dr Tony Fletcher, and Professor Ian Cousins introduced themselves.

Draft report 1, The potential for an interim therapeutic phlebotomy service

Steve Hajioff explained the purpose of this interim report was to assess whether it was evidence-based and appropriate for the Government to make an intervention available for people who had raised levels of PFAS in their blood identified through the testing in 2022. It was noted that it will take longer to look at PFAS impacts on health in detail (report 2) and a larger range of potential interventions (in report 3).

The Panel found that based on the literature they reviewed, therapeutic phlebotomy did appear to reduce PFAS body burden more quickly than it would reduce without an intervention and so the report recommends that Government makes a service available. Steve Hajioff shared the list of recommendations with Islanders and clarified an important distinction; the Panel are not recommending to individuals that they should have therapeutic phlebotomy but are recommending that the government make a service available.

The process of developing the report was built around reviewing and assessing the published scientific evidence. The Panel also took evidence from three people with particular expertise and experience relevant to therapeutic phlebotomy for PFAS. They were; Dr Roger Klein, Professor Kristina Jakobsson, University of Gothenburg; and Professor Jonathan Martin, Stockholm University.

The chair then described the report structure as follows:

1. Introduction
2. Literature review outputs
3. Evidence from subject matter experts
4. Risks and benefits of phlebotomy
5. Discussion
6. Recommendations
7. Appendices

The report also includes a summary, a non-technical summary and a glossary of terms for ease of reference.

Islander input period for Report 1

Steve Hajioff explained that a two-week Islander input period starts now until 25 October and that responses will be included in an appendix of the report. Islanders will not be identifiable, and names will not be used to protect Islander anonymity. Please email PFASpanel@gov.je with your comments.

Recommendations

Steve Hajioff outlined the 10 recommendations of the Panel - *see the report for full details* [Draft first report of the Independent PFAS Scientific Advisory Panel for Jersey.pdf \(gov.je\)](#).

The Panel are recommending that the government make available a therapeutic phlebotomy service to people who had raised levels in the 2022 blood testing programme. With a total of the several PFAS of 10ng/ml of blood. (A total PFAS sum of the 8 PFAS analytes identified in the Jersey blood testing programme).

The Panel also recommended that the Government find out the PFAS background levels in blood in Jersey. Steve Hajioff explained that if someone with high levels of PFAS takes up therapeutic phlebotomy, the service should stop when they reached background levels for the general population, or a reference population. He also talked through other eligibility criteria. Where someone is outside the ages of 16-65 or weighs less than 50kg, the decision about whether phlebotomy is suitable will be made in conjunction with a doctor who leads the service. The Panel recommended that therapeutic phlebotomy should not be offered in pregnancy.

There were questions from the public around water supplies around the island, which Dr Hajioff explained that the panel had not yet reviewed and questions around individual health issues, for which he referred individuals to their own doctor.

There was a comment from the public that in general doctors do not seem to know about PFAS and asked for a toxicologist or expert. Steve Hajioff mentioned that this would be touched on later in the meeting.

Steve Hajioff explained that the Panel was recommending that up to 8 PFAS analytes should be tested before, during and after any therapeutic phlebotomy programme as these are the ones that were shown to be elevated in the affected Jersey population. Iron, full blood count and cholesterol should also be measured as well as monitoring symptoms and a measure of overall wellbeing. Any participants should be asked about clinical history including whether they have participated in blood donation or taken medication to reduce PFAS levels previously.

Steve Hajioff outlined that it is recommended that health care professionals should run any therapeutic phlebotomy service but that how the service will run now sits with Public Health and any potential service providers.

Recapping on the opportunity for Islander input into report 1, Steve Hajioff asked people not to include any personal health information in their responses, for information governance reasons.

Peter Bradley confirmed the role of Public Health in this process. He explained that Public Health are the commissioners of the work, and that they do not amend the report but may ask for clarifications. The report is then taken to Ministers to make the decisions about acting on the Panel's recommendations.

Questions on report 1 The potential for an interim therapeutic phlebotomy service

Comment/question:

There was a concern that over 65s would not be eligible for therapeutic phlebotomy, although it was acknowledged that the recommendations include clinical judgement and flexibility.

- Steve Hajioff reiterated that people aged over 65 should not be automatically excluded from the service, but that the decision about whether they should be included should be made in conjunction with the service, if one is set up.

Question:

A question was asked regarding at what level would you stop therapeutic phlebotomy.

- The Panel explained that they are recommending that an average is taken from samples across the island outside of the plume area to understand the background level in Jersey. The closer an individual's level gets to the background level in the community, the less benefit would be expected from the intervention, so that background level is where an individual should no longer receive the intervention.
- Tony Fletcher explained that the levels are often lower in women because they excrete PFAS more quickly. This is thought to be due, in large part, to menstruation, pregnancy and lactation.

Question:

A question was asked about whether someone who is receiving therapeutic phlebotomy may see their levels go down and then back up because PFAS is in bone marrow and organs.

- Tony Fletcher explained that there was a study in Italy which showed how the levels did go down and then back up shortly after as PFAS redistributed back into the blood from other organs in the body.
- The Panel are recommending testing during and after therapeutic phlebotomy to better understand the impact of phlebotomy on the individual.

Question:

There was a question about stem cell transplant from your own cells.

- The reply given, from Steve Hajioff, was that when you have stem cell transplant the plasma is not taken but the cells are, and then new cells are produced in the bone marrow. PFAS lives in plasma not cells, and so a stem cell transplant would not be expected to result in significant lowering of PFAS levels.

Question:

There were questions about having had blood transfusion and how this effects PFAS levels.

- Tony Fletcher explained that a blood transfusion would involve removing or replacing more of the blood than simply phlebotomy, but as only around a half or less of all the body burden of PFAS is in the blood it would still not take out all the PFAS in one go.

Question:

Further questions covered pregnancy and testing children with health issues.

- Steve Hajioff explained that in report 2, the Panel are looking at vertical transmission, where PFAS may pass from mother to the unborn child and through breast feeding.

Question:

An Islander asked, could our levels have been higher 20 years ago?

- PFAS levels reduce over time through excretion, so it would be expected that levels were higher previously when exposure and intake was higher.
- Overall levels of PFAS in the environment have reduced significantly over time and are much lower now. In the USA, where population levels have been monitored for many years, the average levels were around 20-30ng/ml (nanograms per millilitre) in the 1980s and 1990s.

Question:

If the population average is expected to be around 4 or 5ng/ml, why is the criteria for service eligibility set at 10 ng/ml?

- Steve Hajioff commented that the population average level is not yet known, and the Panel has recommended that an estimate of that should be found. The Panel made the recommendation on the starting level on the basis of a discussion around the scientific evidence. Levels in Jersey were not part of the consideration at that stage but will be important in implementation.

Comment:

There was a comment about cancer prevalence seeming to be higher than in previous decades.

- Steve Hajioff explained that there are many factors in any apparent increase in cancer prevalence, including better information about cases which are there, increasing age and better techniques for finding cancers.

Report 2 An assessment of the impact of PFAS exposure on health

Steve Hajioff outlined the process and explained that the Panel want to hear from Islanders to help stay grounded in the context of their experiences.

Key parts of the process

- Review and analysis of scientific literature
- Testimony from experts by experience
- Evidence from subject matter experts internationally

Key principles

- Being led by science
- Involving input from experts by experience and subject matter experts
- Public involvement throughout the process
- Meetings being in public
- Ability to work in private where there is a need for confidentiality
- Regular engagement with key stakeholders in addition to panel meetings
- No surprises

In the context of involving input from experts by experience, Steve Hajioff explained that in order for information to be used by the Panel in the reports, Islanders have to consent to their data and information being used in that way. He understood that some Islanders were concerned about being identified in the report, and he clarified that any information included in the report would be both anonymous (i.e. would not include names) and also non-identifiable, meaning that information that could allow someone to be identified on the basis of information other than their name, would also be excluded.

In order for the Panel to be able to use testimonies as evidence in the report, consent must be given for the information to be used. All information will be treated as strictly confidential and handled in accordance with data protection rules. Direct quotes from testimonies or meetings may be used for this work and in report publications. Names of individuals providing evidence and any identifiable features will not be included in the report.

Steve Hajioff meets regularly with a small group of Islanders and is happy to meet with other individuals to have a conversation but emphasised that a conversation would not go into the report. Steve reiterated that he cannot give individual medical advice.

Steve Hajioff presented the draft structure of the report for Islander input:

- Introduction and approach
 - Key concepts in environmental epidemiology
 - Systematic literature reviews & critical appraisal

- Understanding risk (at an individual and population level)
- Evidence from the scientific literature
- Evidence to the panel
 - Experts by experience
 - Subject matter experts
- Overall findings by strength of evidence (what areas have the strongest evidence)
- Discussion
- Recommendations

The Chair outlined a list of evidence that is available in the scientific literature, including human body and animal studies for comparison. This is not an exhaustive list and the Panel welcome Islander input.

Call for testimonies from Experts by Experience

Steve Hajioff explained that consent is needed for any data being processed. If the panel interview people in public or private the Panel want to use the anonymous information in the report. Any written testimonies are to be used anonymously and will be destroyed after the final report is completed.

There was a comment from an affected Islander who was not happy about only 8 people invited to give evidence to the Panel.

The PFAS Panel Chair, Steve Hajioff said there are 8 slots to give evidence in public at present. There are also options to give evidence in private and an opportunity to give evidence in writing. Reassurance was given that if the Panel get 10 people wanting to give evidence in public, then they would see if they can fit it in, if 20 come forward he was open to have a rethink. This would need to be within the parameters of providing the report in the agreed timeframe.

At next panel meeting tomorrow (12 October) the Panel will look at the subject areas they need from subject matter experts, for example a toxicologist. The Panel want to hear from experts by experience (affected Islanders) who wish to speak in public on 16 November and 7 December (the private meetings will be on the same dates).

Peter Bradley told Islanders they can speak to him or Grace Norman if there are any queries about the process around the Panels work.

Questions on report 2: An assessment of the impact of PFAS exposure on health

Comment:

An Islander expressed disappointed that Ministers were not present.

- It was reiterated that it was a deliberate decision that Ministers were not present. This meeting is to input and share information with the Panel, and the Panel made the choice not to invite Ministers so as not to impede the information exchange.

Comment:

Islanders asked whether there will be an opportunity soon to meet with Ministers.

- Public Health explained that Ministers will be invited to report launch events, when they will explain their response to the report recommendations. The launch for report 1 will have

Ministers present and is being planned for December. Part of that meeting can be made available for general discussion with the politicians.

Comments:

Islanders believe that government has been asked to protect the PFAS manufacturer from legal action being taken from Islanders and asked to receive a copy of the contract with the manufacturer that they understand exists.

- The Panel explained that their remit does not involve looking back into historical issues and the Panel cannot comment on any relationship between the Government and the manufacturer.
- Peter Bradley reiterated that neither the Panel nor Public Health can assist with this matter, although he will pass on to Ministers that this is a question that Islanders have raised.

Question/Comment:

The Panel were thanked for their work and asked who we speak to today about health advice, as GPs (General Practitioners) cannot help.

- In response, a therapeutic phlebotomy service would help. Report 2 will aim to include information for health professionals that should help them be more informed to support people.
- Peter Bradley commented that he had heard the message that Islanders want support on medical management and information for clinical staff and advice was specifically included in the service specification for the Panel.

Question:

One islander mentioned a file of information that an Islander had created and asked if the Panel will look at it.

- The Panel said that that they had already received some information like this previously and they would be happy to receive more. *[Please send to PFASPanel@gov.je]*

Question:

Is there a time limit for when reports will be produced, or would the process drag on for years?

- Peter Bradley said he could understand the frustration felt by Islanders and the need to get the reports out to inform future work. Islanders were asked for their patience with the process.
- Steve Hajioff said that he was heartened by the fact that politicians agreed to an open process. The timeline is dependent on factors, for example, how many people are interviewed for report 2. He assured people that the work would be completed inside a couple of years.

Comment:

The timing was important as Islanders have been told by lawyers that they have 2 years left to make a case.

- Steve Hajioff commented that report 2 should take around 6 months and will cover the headlines on what the evidence says about different conditions.
- Grace Norman confirmed that there is an expectation that all 5 reports will be done in 2 years from June 2023 (i.e. by June 2025) but noted that it is important to Public Health that the work that is produced is high quality so the work will not be rushed unnecessarily.

Comment:

The PFAS environmental study by Arcadis was referred to.

- Steve Hajioff commented that Arcadis' reports will part of the evidence for report 4 if it is ready in time, and if not, it is expected to be included in report 5.

Question:

Would you accept that you found no published evidence on health benefit of therapeutic phlebotomy and relied on inference?

- Steve Hajioff explained that the science does not link reduced blood levels with future health outcomes (e.g. heart attacks).
- Tony Fletcher commented that for a disease that may happen in future you can often only work through the inference of expert knowledge.

Question:

The people in the testing programme already had symptoms and you can't prevent a disease you already have. How can the body improve after therapeutic phlebotomy?

- Steve Hajioff commented that secondary prevention - managing severity and complications of disease – may be important for some people, and some disease processes are reversible.
- The Panel reiterated that they are not recommending that people have therapeutic phlebotomy, but rather are recommending that Government offer a service.

Question:

Is it right that others were not tested who did not have symptoms?

- Steve Hajioff said that wider testing would be picked up in later review [report 3].

Question:

Can government contact the 88 islanders who were tested to tell them this information?

- Grace Norman explained that Public Health can only contact people directly who have provided their email or postal address to receive communications and had to be mindful of data protection rules. To be added to the mail list please email publichealth@gov.je or add your details to the form at public events.

Comment:

Islanders have lost family members and pets; could the Panel accept testimonies on behalf of those who have passed away?

- Steve Hajioff said that they would hear information about people who have died as part of the testimonies from their family members or others.

Closing and summary

For report 1:

- Ministers will consider report 1 shortly
- There will be a launch event in December where Ministers will explain the decisions they have made about the recommendations from report 1

For report 2:

- Next Panel meeting is 12 October at 10am
- Invite testimonies from Islanders by 25 October please email PFASpanel@gov.je
- Review evidence from Islanders
- Hear from experts by experience on 16 November and 7 December from 10am (in public or in private)
- Invite subject matter experts to give evidence to the Panel
- Review global evidence
- Commence drafting process for report 2

Process:

- If you wish to be added to the PFAS Public Health newsletter distribution list, please request it by emailing publichealth@gov.je
- The slides will be available on the website, here: [PFAS in Jersey \(gov.je\)](https://www.gov.je/PFAS)

The Panel and the support staff were thanked for their work, and the meeting was closed.