

Witness Name: Professor Chris Jones
Statement No.: WITN4065001
Exhibits: WITN4065002-WITN4065003
Dated: 11 February 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PROFESSOR CHRIS JONES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules dated 10 January 2020:

I, Prof Chris Jones, Deputy Chief Medical Officer, Welsh Government, will say as follows:

Part A: Provision of Psychological Support

1. Psychological services are commissioned and funded in Wales as follows:

2. Local Health boards have responsibility for planning and delivering health services dependent on population need, this includes psychological therapies. In Wales, mental health funding is ring-fenced within the main NHS allocation and improving access to psychological therapies remains a priority for health boards.

3. As part of the delivery of health care for physical conditions, we expect health boards to provide patients with support to manage their condition, including the psychological impact of their disease. Psychological therapies in Wales are commissioned and delivered in line with Matrics Cymru – guidance for the delivery of evidenced based psychological therapies in Wales:

<http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/Matrics%20Cymru%20%28CM%20design%20-%20DRAFT%2015%29.pdf>

4. Psychological services are not the commissioning responsibility of the Welsh Government.

5. Psychological Support is provided specifically for beneficiaries of the Welsh Infected Blood Support Scheme (WIBSS), through funding provided by the Welsh Government. The Minister announced the provision of this service in March 2019 [WITN 4065002]

6. WIBSS is hosted by Velindre University NHS Trust. The Trust have considerable experience in providing such a service as part of their remit as the cancer centre for Wales.

7. The Welsh Government, WIBSS, Velindre UNHS Trust and stakeholders worked together to produce a blueprint for the psychological services that are required to meet the needs of those infected and/or affected together with their families. A proposal was taken to the WIBSS Governance group and approved. [WITN 4065003]

8. The WIBSS Psychological Support Service began seeing beneficiaries and family members in December 2019. The service has continued to develop its standard operating procedures, referral process etc. All patients who had previously requested such support were contacted and informed about the service. Those beneficiaries or family members deemed to be of high risk were seen as a priority by either the consultant psychologist or lead counsellor. The WIBSS website was updated to reflect the new service and meetings arranged with key stakeholders in Health Boards, 3rd sector etc.

9. The feedback from those accessing the service has been extremely positive. Formal mechanisms for measuring outcomes and experience are in place and will be reported to the Governance group on a quarterly basis.

10. The WIBSS website details the psychological services as follows:

"A psychology team specifically for the service has been established. From January 2020, individuals registered with WIBSS, their family members and bereaved family members can access psychological assessment and treatment concerning the emotional difficulties of being given and living with a diagnosis of Hepatitis C and/or HIV. The team are aware of the historical context and have experience of working with the emotional difficulties that have occurred as a result. A hope is that by offering a specialist psychology service there will be some acknowledgement and recognition of the physical and psychological complexity and the impact on quality of life and relationships. Following a referral to the psychology team an assessment appointment will be offered which will be an opportunity to talk through the previous and current emotional difficulties and consider options for treatment going forward. The psychology team are able to offer a telephone conversation before and after referral if there are any questions or concerns about what to expect from a psychology assessment and/or treatment."

Part B: Treatments for hepatitis C virus and follow-up care

11. HCV treatment is commissioned and funded in Wales as follows:

Hepatitis C Virus (HCV) treatment is commissioned and funded by the health boards through their central resource allocations provided annually by the Welsh Government. The Welsh Government allocated additional resources to health boards for the new antiviral medications in 2015/16. Funding was allocated in line with anticipated health board treatment demand and there was no cap put on the number of patients that could be treated within any health board.

12. Details of the current treatments that are available for HCV in Wales, their effectiveness and availability, including any restrictions and/or delays that may be experienced in accessing treatment are as follows:

There are no restrictions on individuals receiving treatment. There is equitable and transparent access to treatment across Wales. Treatment is chosen by the clinician in partnership with the patient. Treatment can be offered to active injecting drug users and is increasingly available within the Welsh prison estate.

13. There are national guidelines in place which encourage clinicians to choose the most appropriate treatment for the patients and where treatment options are equally appropriate to choose the most cost effective option. The effectiveness of treatment is in the order of 95%. Where follow up data is available treatment outcomes in Wales have been shown to be at least as effective as treatment outcomes in other major European centres.

14. When the new medications were first released in 2014/15 there was a backlog of patients to treat and initially patients were treated according to clinical need. All patients presenting for treatment that, for clinical reasons could not wait for treatment, were treated immediately. There is currently no waiting list for treatment in Wales.

15. *What scans, blood tests and/or other checks and/or monitoring are, or should be, offered to a person who has been diagnosed with HCV, how often and over what period of time?*

This depends somewhat on the patient's circumstances and choice. In general where possible the following pathway is followed:

- Baseline blood tests including urea and electrolytes (U&E), liver function tests (LFT), estimated glomerular filtration rate (eGFR), international normalised ratio (INR), full blood count (FBC), viral load and genotype and fibroscan (performed in a one stop clinic).
- Review patient with results (2-4 weeks for results) and medication ordered according to results.
- Treatment commenced 2 weeks later (delivery time 2 weeks).
- Review patient early in course of treatment (2-3 weeks after starting) to check patient is tolerating treatment, compliance, repeat routine bloods (FBC, U&E, LFT, viral load).
- Further follow up at the discretion of the treating clinician in partnership with the patient.
- Review patient 12 weeks after treatment has finished for blood tests to confirm success of treatment (FBC, U&E, LFT, viral load).

16. An accelerated / light touch pathway exists for use in certain circumstances where attendance at a clinic is more difficult or if a patient would prefer such a pathway. Baseline bloods including U&E, LFT, eGFR, FBC, INR, viral load, genotype and fibroscan (performed in a one stop clinic) and pan-genotypic treatment started. The patient is reviewed 12 weeks after stopping treatment to confirm success of treatment (FBC, U&E, LFT, viral load). In this pathway the patient can choose to be seen during treatment or if patient has any side effects / needs to be seen (patient has contact numbers to book an urgent appointment).

17. *Following successful treatment, such that the person has received a sustained virological response (SVR), what follow up scans, blood tests and/or other checks and/or monitoring are or should be offered, how often and over what period of time?*

This depends on the patient's level of disease prior to treatment. If the patient has no or minimal damage to the liver prior to treatment then the patient is discharged back into the community as no follow up is required. If the patient has advanced liver disease then they would be followed up appropriately by that service (i.e regular scans for hepatocellular carcinoma (HCC) and regular monitoring with hepatology). Further later date blood borne

virus (BBV) testing is also recommended if a patient continues to engage in injecting drug use following treatment.

I believe that the facts stated in this statement are complete and accurate.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed _____ GRO-C

Dated 11/2/20