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Subject Blood testing following criminal incidents where there is a risk of infection
Reference MLLEG1

Dear Sir/Madam

The following letter provides Mainliners response to the circulated proposal for legislation on 'Blood Testing following Criminal Incidents where there is a risk of infection'. Mainliners is a national HIV and hepatitis Charity which has 15 years experience working to reduce harm from blood borne viruses and substance misuse. The organisation operates the UK Hepatitis C Resource Centre and a range of sexual health, housing and substance misuse projects.

Mainliners applauds the Scottish Police Federation for their wish to reduce the distress and anxiety that individuals and their families face following a exposure incident and indeed for recognising and acknowledging this fact. The fear of infection from a Blood Borne Virus (BBV) is usually much larger than the risk itself. However, the potential consequences of an exposure incident have significant impact on an individual and their family which permeates into many areas of their lives. It is naturally very difficult for those concerned to put their anxiety into perspective when taking the day to day precautions that are necessary until their loved one is given the all clear from tests six months later. Mainliners recognise this and works closely with individuals from all walks of life to reduce their emotional distress as much as possible through education, support and advice.

Mainliners shares the aims of the Scottish Police Federation to protect individuals from exposure to BBVs and to reduce the anxieties and distress that are experienced following potential exposure by all concerned be they police officers, family members, health care workers or prisoners. Mainliners have therefore reviewed the proposed legislation with much interest considering the options available and the need to implement a system that will balance protecting individuals from exposure and harm whilst safe guarding the rights of all concerned to fair treatment and confidentiality.

It is therefore with some regret that although Mainliners agree with the aims and objectives of the legislation, we are not in favour of the proposal in terms of its approach and the methods to implement it. We believe the Scottish Police Federation has chosen a route that will significantly heighten concern (converse to its objectives) and will do little to assure the care and emotional support of those concerned. Of particular concern, Mainliners feels that the legislation may set a dangerous precedent for testing and

disclosure of an individual's blood borne virus status without their permission well beyond the settings envisaged by the authors.

Mainliners believe the aims and the objectives of the legislation are sound but unfortunately the suggested methods and approach to deliver these are unnecessarily heavy handed. The authors lack of understanding of BBVs is demonstrated at several points in the document leading Mainliners to recommend the need for procedures, education and guidance on BBVs to be revised within the Police Force in Scotland. In Mainliners opinion, the testing agenda that drives the methodology of the proposal will provide little additional information at the time of exposure to influence treatment and care decisions. This is due to the unreliable nature of current BBV tests at the time of exposure (see B.1) which were not addressed.

Mainliners are of the opinion that Mandatory testing will therefore bring little benefit to either party. We note with disappointment that the proposal did not review considerable other options regarding improved care and support mechanisms in the community with experts in the BBV field. This is a significant oversight which likely contributed to the shortfalls in the proposal.

Section A – Mainliners Grounds for Opposing the Tabled Legislation

Mainliners is regrettably opposed to the legislation of the following grounds:

1. The proposal is unjustified.

Mainliners believe there is little to be gained by testing individuals for a BBV at the time of exposure due to the acknowledged viral incubation periods which make test results unreliable at this stage (see B.1 below). The authors have not addressed this in their proposal despite its detrimental impact on the argument for mandatory testing. Test results for BBVs are unreliable until 3-6 months post exposure. In doing so, the authors have not weighed the limited benefits of mandatory testing (to assist treatment and care decisions) with the negative consequences of testing, diagnosing and disclosing another individual's BBV status without their permission. The legislation therefore breaches the rights of individuals to make an informed decision about BBV testing and their right to medical confidentiality with little to be gained.

2. The proposal is disproportionate towards the needs of the applicant.

Mainliners is of the opinion that the proposed legislation has not considered the greater ramifications of mandatory testing and the precedence this legislation will set. The concerns of all parties involved in an exposure incident are naturally complex but they have not been considered with equal weight by the authors, introducing bias. By way of example, the proposed legislation does not address the concerns of the public to infection from police officers during exposure incidents and the recourse of the public to therefore seek the mandatory testing and disclosure of an officer's BBV status.

The proposal has also not addressed the serious and justifiable concerns of the individual to be tested against those of the applicant, regardless of who is the *alleged* victim or

suspect. In this respect, Mainliners note that all parties are legally innocent at the stage of asking for mandatory testing so the terms 'suspect' and 'victim' are misleading and inappropriate to what is an issue of health and confidentiality rather than justice.

3. The proposal provides no safe guard for limitation of the legislation.

The proposed legislation has not been limited to exposure incidents where there is an alleged deliberate (criminal) intent to infect. Hence, applications for mandatory testing can be presented to a Sheriff for any exposure incident warranting concern. Mainliners feel this consequently leaves implementation of the legislation and the process of seeking permission from the Sheriff open to significant interpretation which we do not find acceptable for legislation of this nature. Furthermore, Mainliners would question how a Sheriff, an expert in law, will determine if the exposure warrants mandatory testing. This is surely a decision to be taken by a BBV expert who has the knowledge and experience to properly determine if the risk is significant.

A further concern which Mainliners wishes to raise is the real possibility that this legislation will provide a precedent for medical testing and disclosure without the need to seek permission from individuals in circumstances other than those envisaged by the authors. It provides the possibility for legal challenges from members of the public seeking mandatory testing and disclosure of the BBV status of individuals following exposure incidents which do not necessarily involve police officers. It will become difficult to deny this recourse on a more general basis for other settings. After all, the distress and risk to members of the public from an exposure incident would naturally be considered equal to the distress experienced by police officers and their families which is described as the basis for this legislation. It will therefore be difficult to legally restrict the application of this legislation to the situations envisaged by the authors. Mainliners feel the legislation will therefore provide a precedent that goes well beyond the remit of the police force.

4. The proposal does not assure an effective health care response.

Mainliners is of the opinion that the proposal will not provide an effective healthcare response for officers and members of the public in relation to their potential infection from a BBV. The emphasis is on testing at the time of exposure and does not consider the limited information that testing can bring to assist decisions regarding care and treatment at this time. Mainliners believe it is the nature of the exposure rather than the test result which should determine treatment, care and advice for those exposed since testing remains unreliable at the time of exposure (see B.1).

5. The proposed legislation will undoubtedly and unnecessarily raise anxiety.

Mainliners provides education and raises awareness of hepatitis C through partners across sectors in the UK. All recognise the need for care in the messages that are given to the public to encourage education and testing. Mainliners is of the opinion that mandatory testing wrongly enforces a message that there is a high risk of infection from an exposure incident in the circumstances outlined by the authors (eg. biting, needle stick, coughing, spitting). There is a need to promote universal and sensible precautions to prevent the spread of blood borne viruses but this must be based on the evidence of the epidemiology and research that is well documented. Based on this, the nature of the exposure incidents

highlighted by the authors pose a low risk of infection which is entirely converse to the perception that will be promoted by both mandatory testing and the efforts that will be made to secure a test. Why would the legislation go to this length to secure mandatory testing if the risk were not high, is a logical and inevitable conclusion.

6. The proposal will increase stigmatisation and discrimination

Individuals from across all walks of life are infected or affected by a blood borne virus for many different reasons. In Scotland alone there are around 45,000 individuals infected with hepatitis C and 3,000 infected with HIV. Ironically public perception is still heightened towards HIV which is less common and less infectious.

The proposed legislation will undermine the efforts by organisations such as ourselves and HIV Scotland to reduce the stigma and discrimination faced by those living with a BBV infection through education. It will disadvantage further efforts to encourage testing amongst the most at risk groups which does little to protect all concerned long term. Refer to B. 5 for further details.

7. It associates BBV testing with criminality instead of health and well being.

Mainlines has much experience of working with individuals who are at risk of hepatitis and HIV and the difficulties in encouraging them to come forward for testing. Many are isolated and fearful or suspicious of testing, institutions providing testing and the consequences of diagnosis. The connotations of mandatory testing via the police force will associate BBV testing with the Department of Justice rather than the Department of Health in the eyes of the public. This markedly reinforces stigmatisation of those living with a BBV infection and will further discourage members of the public from coming forward to be tested in a healthcare setting because of an association with criminality. Many individuals living with a BBV become socially isolated through stigmatisation and personal experience of discrimination. Those considering testing are usually extremely vulnerable so associating testing with crime will undo the efforts of many over the last 15-20 years to encourage individuals to seek testing, help and care.

7. The proposal breaches an individual's right to choice regarding their health and confidentiality.

Mainlines firmly believes that the proposed legislation overrides an individual's right to determine if they are ready to be tested for a BBV despite the fact this can be very damaging to the individual concerned. It is well recognised in the BBV field that many individuals need to be gradually prepared and counselled prior to testing and diagnosis which can take time depending on other health and socioeconomic concerns.

The proposal also overrides the need to obtain permission from the individual to disclose their BBV status to others. This is a big departure from normal medical ethics that has far reaching consequences beyond the Police Federation. It breaches confidentiality purely in the interest of the applicant. Disclosure of an individual's BBV status, as proposed in the legislation, poses a very real danger of further disclosure beyond the police setting that is surely not unacceptable.

Section B – Supporting Information To Mainliners Objections

1. Testing and the influence of viral incubation periods

The incubation period for HIV is 3 months compared to 6 months for hepatitis B and C. Tests for these viruses are not sensitive enough to provide accurate results during these incubation periods. Consequently, any negative test result at the time of exposure is not reliable and cannot be used to diagnose that a person is free from infection to make a decision about Post-Prophylactic Treatment (PEP) for HIV. It can only say that the person tested *may* not be infected until the test can be repeated after the incubation period has passed. Individuals may simply not have had the virus long enough to make it detectable until after the incubation periods have passed.

Any decision to (a) administer PEP and (b) the nature of the advice and support to provide to officers cannot therefore be based on blood testing at the time of exposure. These decisions should be based on the 'risk' of infection based on the details of the exposure itself. Mainliners strongly recommend that these decisions are made by a specialist in the BBV field such as hepatologist, gastroenterologist or consultant in infectious diseases. Decisions need to be made by a professional with a depth of knowledge regarding BBV infections, risk and treatment.

2. The Time Scale to Administer PEP

HIV PEP needs to be administered within h of exposure. This is not feasible by this proposal because of delays incurred to:

- a) Present each case to a Sheriff and for them to consider the application and consequences of permitting a mandatory test.
- b) Provide pre-test counselling to the individuals from which blood will be taken for testing. This needs to be given before a blood sample is taken in line with standard practise in the NHS and elsewhere. The provision of pre-test consultation is noticeably absent from the proposed legislation. Pre-test counselling should not be denied (providing sub-standard care) because testing is being undertaken out with a health care setting.
- c) The test itself needs time especially for hepatitis C where there is no rapid test kit (not covered in the proposal)

3. BBV Risk and Transmission

The premise of the proposed legislation is to providing testing as a mode of reducing the anxiety of those involved in an exposure incident. The proposal will not achieve this and will conversely heighten fear amongst the public, officers and their families because the need to recourse to mandatory testing promotes the premise that the risk of infection must be high.

The author highlight need stick injuries, biting, coughing and spitting as exposure incidents. The risk of infection from BBVs through needle stick injuries is extremely low (only 2% for hepatitis C which is the most infectious virus via this route). The risk of infection from other routes such as spitting, coughing and biting is much lower still. Mandatory testing at the time of exposure will unfortunately underline the perception that the risk of a BBV infection is high regardless of the nature of the exposure. This fuels rather than reduces anxiety for all parties.

4. Impact of Diagnosis

BBV diagnosis can cause significant trauma to vulnerable individuals. As a result of this, pre and post test consultations are provided as a standard of care to anyone undergoing testing in the voluntary sector and statutory health care settings. Forcing individuals to undergo BBV testing when they are not ready to do so can be extremely detrimental to the health and well being of the individual that should not be underestimated.

On this basis, the negative impact on the health and well being of the individual being tested is more likely to outweigh the limited benefits gained from disclosing their BBV status.

5. Stigmatisation and Decimation of those living with a BBV infection

6. Alternatives to Mandatory Testing.

The proposal does not provide an alternative to the use of mandatory testing to reduce anxiety which makes it difficult to determine if other options were in fact considered.

One option is to counsel officers and close family members on their low risk of BBV infection with a recommendations for simple day to day precautions until the officer has some routine BBV tests at 3 and 6 months as a precautionary measure. The provision of information and support in this way will have more impact in reducing anxiety.

The provision of support and information immediately after exposure and at times during the 3-6 month viral incubation periods is routinely offered elsewhere in the statutory and voluntary sectors to effectively tackle post-exposure anxiety. This is usually extended to close family members to ensure the family unit as a whole is also adequately supported and that simple precautions are undertaken until tests are undertaken as a precaution at 3 and 6 months.

Section C - Mainliners answers to the proposed legislation questions

Question 1. Do you agree that any legislation giving rights to individuals to apply for information about blood-borne viral infections with which they may have been infected, should apply universally? Or should the protection be restricted to particular groups of people? If the latter, what groups should it be restricted to and what would be the justification for this?

Mainliners does not agree to any legislation that gives one individual the right to apply for information about another person's blood borne virus status. We agree in principal that all legislation should be implemented universally to avoid stigmatising and discriminating particular groups of individuals and to avoid complacency on the part of officers dealing with individuals that they perceive to be less likely to have a BBV infection. However, we strongly oppose the implementation of any legislation based on mandatory BBV testing for the reasons outlined above after considering the methods and approach to be used in implementing the legislation.

Question 2. Do you agree that mandatory blood testing should only be ordered by a sheriff?

Mainliners do not agree that mandatory testing should be implemented. We recognise the role and value of the Sheriff to assure fairness and consistency in reviewing applications for mandatory testing. However, Mainliners does not agree to the ordering of mandatory testing by a sheriff. Firstly because Mainliners are opposed to the use of mandatory testing as outlined above. Secondly, the involvement of a Sheriff is impractical in the timescale needed for HIV PEP administration. Thirdly, the sheriff is not an expert from the BBV field and hence is not an authority to determine whether an incident presented to him entailed a significant BBV risk to the officer or member of the public concerned on which to base their decision.

Mainliners recommend that a BBV professional should always determine the level of risk from an exposure incident and the nature of the care and treatment to be provided to each party. The provision of information and support for each party following exposure should also be provided by BBV agencies and services who have the experience to deliver this effectively as part of a care pathway.

Question 3. Do you agree that mandatory blood testing should not be applied to anyone who has committed no crime but may *accidentally* have exposed another person to a prescribed blood-borne viral infection, so that such people should be free to decline to give a blood sample?

At the time of applying for a mediatory test order, all parties are legally innocent so Mainliners feel this question is quite misleading. Mainliners also note that this question indicates that the legislation is based on a premise that an individual must waive their right to medical confidentiality if they have committed a crime. Mainliners disagrees with

this principle and does not accept that one individual has the right to apply for disclosure of the BBV status of another individual, regardless of whether either party has been charged with a criminal offence.

Mainliners is unaware of any other medial condition where an individual has to disclose their status to the police force against their will. Mainliners is equally unaware of any other medial condition where the Police Federation has taken a criminal charge to mean that an individual must waive their right to medical confidentiality. Mainliners is opposed to BBV infections being used to set such a precedent and the institutional discrimination that this employs.

Q4 Question 4. Do you agree with the principle of mandatory blood testing for those who commit serious physical or sexual assaults and thereby put the victim of the crime at risk of infection with a prescribed blood-borne virus?

Mainliners does not agree with this principal. Again, Mainliners recommend that anyone at risk of a BBV infection is assessed and cared for by a BBV specialist so that they may assess the level of risk that the person has been exposed to and can then provide the necessary care and treatment as soon as possible. Mainliners does not agree that mandatory testing should be applied as the benefits are minimal and the delays impact on the speed and effectiveness of the care that can be offered in the short term to the individual concerned.

Question 5. Do you agree that the provisions for mandatory testing should extend to any type of case where the applicant may have been exposed to a prescribed blood-borne viral infection as a result of a crime being committed by the other party?

Mainliners does not agree with this principal. As above, the benefits of mandatory testing are not justified. Mainliners recommend that anyone at risk of a BBV infection is assessed and cared for by a BBV specialist so they may assess the level of risk that the person has been exposed to and can then provide the necessary care and treatment.

Question 6. Do you think there should be any variation in these provisions for cases where the suspect is under age?

Measures to safeguard individuals that are underage include the presence of an adult when the youth is being held by police and for any procedures being undertaken that involve that youth. In doing so, this immediately poses the risk of the BBV status of the young person being disclosed to their accompanying adult without their permission.

Mainliners feels that the added care and complexities of testing and diagnosing an underage individual need more detailed consideration and care than can be secured through this proposal.

Question 7. Do you agree that persons at risk of infection from a criminal incident should be entitled to seek information from the Procurator Fiscal about the prescribed blood-borne viral infection risks they may face?

No, Mainliners disagree with this. As above Mainlines feel that a Procurator Fiscal is not an expert in the field of blood borne viruses and should therefore not provide advice to any individual on BBV infection risk. Mainliners strongly recommend that this information is provided by a specialist in the BBV field such as hepatologist, gastroenterologist, consultant in infectious diseases or a specialist BBV or hepatitis nurse. In doing so, the BBV status of any party must not be disclosed without their permission as is standard practise in the NHS and elsewhere.

Question 8. Do you agree with the proposed criteria for mandatory testing orders?

Question 9. Do you have any comments on the proposed civil application process?

Mainlines agrees with the right of an individual to appeal an order for mandatory testing and the safe guards this facilitates, However, the process of appeal again adds a time delay making the legislation impractical in terms of HIV PEP administration and the premise of assuring a health care response for those at risk.

Mainliners disagrees with provisions in the legislation that enable courts to fine or imprison anyone refusing to undertake a test. We believe this is highly inappropriate since many individuals living with a BBV infection are unwell or have poor socioeconomic circumstances meaning that a fine or imprisonment are severe tools for this purpose and are totally disproportionate to the benefit gained to the applicant. These provisions hold up the individual and BBV testing as a criminal issue rather than a health matter to which Mainliners strongly object.

Mainliners oppose any measure in the legislation that allows an individual's BBV status to be disclosed to another party. The proposal outlines the 'Liberty to pass this information on to others' on the part of the applicant' This is a clear breach of an individuals right to medical confidentiality which underlines Mainliners concern that this right is being disregarded in a discriminatory manner against those potentially infected with a BBV.

Question 10. Do you agree that information provided from mandatory testing orders should be for the sole purpose of benefiting the applicant, and should not be retained by the police?

Mainliners is of the opinion that any information resulting from a mandatory testing order should not be retained by the police. Furthermore, Mainliners does not agree that the information is for the sole benefit of the applicant. Mainliner disagrees with this information being disclosed in any way to the applicant as it breaches another person's

right to medical confidentiality. We would again express our concern that there is the real risk of further disclosure of an individual's BBV status and resulting discriminatory actions.

Conclusion

In concluding, Mainliners feel that the authors have unfortunately missed an excellent opportunity to develop a more effective proposal through consultation with experts across the field of blood borne viruses. There is a notable lack of understanding of blood borne viruses, their risk of transmission and the tests used to diagnose infection in the proposal that causes some concern.

Mainliners hope it is not too late for the Scottish Police Federation to consult with BBV experts and that they may prepare a more effective and acceptable legislative proposal for all concerned.

Mainliners shares the aims of the Scottish Police Federation to protect individuals from exposure to BBVs and to reduce the anxieties and distress that are experienced following potential exposure. We would like to help in this regard to ensure a proposal is developed that can indeed provide improved information support and care for officers and indeed others involved in an exposure incident to ultimately reduce their distress and concerns as far as possible.

In this respect, we hope our response provides is of help and provides some feedback for your consideration. If you have any queries please don't hesitate to contact me. I will be happy to provide any further assistance.

Respectfully



Dr Nicola Rowan
Mainliners UK Hepatitis C Resource Centre (Manager)