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Health Select Committee – Lord Archer’s inquiry and criticism of measures to tackle hepatitis C

Issue

1. At the HSC hearing on 25 July, David Amess MP asked SofS and Lord Darzi to take note of the findings of Lord Archer’s independent inquiry into contaminated NHS blood and blood products, and criticised Government action to tackle and raise awareness of hepatitis C. SofS offered to write to Mr Amess on these points.

Background

2. Lord Archer is chairing an independent public inquiry into the contamination of NHS blood and blood products. The inquiry opened on 27th March when it was expected to take three to four months. We now expect it to be extended until around the end of the year. The main focus of the inquiry is the extent and cause of contamination of NHS blood and blood products with hepatitis C and HIV in the 1970s and 1980s. (Further details of the inquiry and the Department’s response are at Annex A.)
3. David Amess gave evidence to the inquiry on 11th July and indicated that he would raise these issues at the HSC hearing. In the event he focused mainly on the current DH Hepatitis Action Plan for England awareness campaign. (Further briefing on hepatitis C and the Action Plan is at Annex B.)
4. David Amess is co-chair of the All Party Parliamentary Hepatology Group (APPHG). APPHG has lobbied DH in the past about hepatitis C, prompted by the main voluntary sector organisation in this area, the Hepatitis C Trust (chief executive – Charles Gore), which provides the secretariat to the group. Caroline Flint, then MS(PH), met with David Amess and the other APPHG co-chair Bob Laxton in November 2005

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to discuss hepatitis C and subsequently kept them informed about relevant developments.

5. Charles Gore has recently written to SofS calling for a higher priority to be given to hepatitis C through the setting of central targets for the NHS and a much expanded awareness campaign. However, DH Ministers have not seen central targets as appropriate when actions are mainly locally driven in response to local needs. However, the Department has committed considerable extra central funds to support the awareness campaign and improved epidemiological surveillance. A draft reply to the Hepatitis C Trust is with Customer Service Centre making similar points to the attached response to David Amess.

Action

6. A proposed reply to David Amess is attached.

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Draft reply to David Amess MP

Dear David

At the HSC hearing on Thursday you asked if I would take note of the findings of Lord Archer's independent inquiry into contaminated NHS blood and blood products. I can assure you that we will do so. The Government has great sympathy for those infected with hepatitis C and HIV in the past and we are doing what we can to assist the inquiry. My officials have met with the inquiry team and offered to answer any specific questions that they may have.

In addition, in May this year my Department issued a review of documentation held by my Department concerning the safety of blood products in the years 1970-1985 in relation to Non-A Non-B hepatitis (as hepatitis C was then known), together with a set of official documents referenced in the review.

We subsequently took the decision to go further and issue all of the documents identified during the review, in line with the provisions of the Freedom of Information Act. These cover issues such as the development of NHS capacity to manufacture blood products, the emergence of HIV as a new challenge for NHS blood and blood products, and measures taken in response. Two sets of documents have been issued to the inquiry team and a third will be issued early in August. We expect that all of the 4000 or so documents will be issued by early September. Those issued so far can also be viewed on the Department's website at http://www.dh.gov.uk/en/Publicationsandstatistics/Freedomofinformationpublicationscheme/feedback/FOIreleases/DH_076693#_1

We aim to be as open as possible about the events leading to contamination of NHS blood and blood products in the past, and will take note of the inquiry's evidence and conclusions in due course.

You also asked about Government action to tackle hepatitis C, including raising public awareness.

I can assure you that the Government recognises the public health importance of hepatitis C. This is why we set a clear national framework for action to improve the prevention, diagnosis and treatment of hepatitis C in the *Hepatitis C Action Plan for England*, published in 2004.

Responsibility for implementation of the Action Plan at the local level lies with Primary Care Trusts and their local partners. They are best placed to assess what is needed in their areas and take account of other priorities. We have asked Strategic Health Authorities to ensure that local arrangements are in place to provide appropriate services. On a national level, the Health Protection Agency will be tracking the impact of the Action Plan through epidemiological surveillance.

We have provided central support for key aspects of implementation of the Action Plan, such as an awareness campaign for healthcare professionals and the public, on which we have spent about £4 million to date.

The hepatitis C awareness campaign (FaCe It) is using a variety of communication methods to inform healthcare professionals and the public about hepatitis C. The campaign has so far included, for example:

- a hepatitis C information pack for GPs and practice nurses, followed up by a quick reference guide on hepatitis C for primary care published earlier this year;
- a new NHS awareness website - www.hepc.nhs.uk
- a new national hepatitis C freephone information line;
- advertising in national press and consumer magazines and on regional and local radio;
- features in health care professional journals, regional/national newspapers and consumer magazines;
- publicity in consumer magazines;
- exhibition stands at conferences for healthcare professionals;
- an innovative photography exhibition of portraits of people with hepatitis C that has been touring cities and towns using local patient case studies to generate regional and local media coverage.

It is encouraging that the awareness campaign appears to be leading to increased diagnosis of hepatitis C, which is one of its key aims. There has been a significant annual increase in hepatitis C diagnoses in England reported to the Health Protection Agency through national surveillance from around 4,700 in 2001 to around 7,600 in 2005. Other epidemiological surveillance data suggest that diagnosis of hepatitis C is increasing. For example:

- sentinel surveillance of hepatitis C testing in nine laboratories from 2002-2005 indicates that overall the number of individuals tested for hepatitis C increased by nearly 40%. Testing by GPs and in genitourinary medicine services both increased by over 50%, and in prisons by around 65%.
- In the unlinked anonymous prevalence monitoring programme, the proportion of injecting drug users attending specialist services who self-report a previous hepatitis C test has increased from 57% in 2002 to 71% in 2005.
- proportion of injecting drug users attending treatment and support agencies who are aware of their hepatitis C infection. The proportion of are aware of their hepatitis C infection has increased from 42% in 2002 to 52% in 2005.

Research among GPs and practice nurses and the public indicates that awareness has increased since the campaign began. However, I know that more needs to be done, and so the awareness campaign is continuing in

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2007/2008 and will include further advertising. We will be spending around £2.75 million on the campaign in the current financial year, in addition to the £4 million spend so far.

My Department is, therefore, fully engaged in supporting the NHS in its drive to improve prevention, diagnosis and treatment of hepatitis C.

ALAN JOHNSON

Annex A. Lord Archer's independent inquiry into infected blood products

1. Lord Archer is chair of a non-governmental public inquiry into contaminated blood and blood products. The inquiry was opened on the 27th March 2007 and was estimated to take 3 to 4 months. We expect this to be extended until around the end of the year.
2. The Department is co-operating with the inquiry. Officials met with Lord Archer and colleagues on 25th April 2007 and a further offer to meet has been made.
3. The Department issued a review of documentation held relating to the safety of blood products (1970-1985) in May this year. Around 1,600 official documents identified by the review have already been released to the inquiry; the remainder will be released as soon as they have been prepared. It is our intent to release as many of these papers as possible, including submissions to Ministers and policy formulation.
4. The Haemophilia Society has submitted evidence to the inquiry and provided a copy to the Department. The focus is on a series of delays: in achieving self-sufficiency in plasma products, introduction of heat-treatment to inactivate HIV, introduction of screening tests for hepatitis C and HIV.
5. The Haemophilia Society believes that there should be a full Governmental public inquiry into the issue of contaminated blood products and hepatitis C, and argues that their case is supported by the fact that some relevant papers are missing. They have lobbied extensively to that end.
6. Successive Secretaries of State have resisted calls for a government backed public inquiry into how patients became infected with hepatitis C following NHS treatment with blood and blood products prior to the introduction of heat treatment to eliminate the hepatitis C virus on the following grounds:
 - A full judicial inquiry would be a major, costly and time-consuming exercise that would depend on the recollections of witnesses about events that took place twenty or more years ago. This would make it difficult to construct a clear and detailed picture of what took place.
 - An inquiry would not add significantly to our current understanding of how the blood supply became infected with Hepatitis C, or the steps needed to deal with problems of this kind now or in the future.
 - There is no evidence that any wrongful practices were employed. The release of a significant number of papers, with a minimal number withheld, could provide much of the information sought by interested parties.

Annex B. Hepatitis C and current measures

A. Key Facts

Hepatitis C and how it is spread?

- Hepatitis C is a virus that can infect and damage the liver. The virus is found in the blood of people who have the infection. Hepatitis C is spread primarily by contact with the blood of an infected person. Currently the main route of transmission in the UK is by the sharing of contaminated equipment by injecting drug users.
- Other less common routes of transmission are:
 - from an infected mother to baby at birth;
 - by unprotected sexual intercourse with an infected person; and
 - by skin piercing and tattooing when sterile equipment is not used.
- Theoretically, household spread is also possible via the sharing of blood contaminated toothbrushes and razors.
- Before the viral inactivation of blood products in 1986, and before 1991 when the screening of blood donors was introduced, some recipients of blood and blood products were inadvertently infected.

How serious is hepatitis C infection?

- Hepatitis C infection is cleared in the acute stage by about 20-40% of those infected, but persists in about 60-80% to become chronic infection. Some of those with chronic infection will have only mild liver damage, many with no obvious symptoms. Many people with chronic hepatitis C infection will live out a normal lifespan.
- 5-20% of patients with chronic infection will develop cirrhosis after 20-30 years. Of these, a small proportion will develop primary liver cancer (about 1-4% per year).

What is the estimated prevalence and incidence of hepatitis C in this country?

- The prevalence of hepatitis C in this country is relatively low. Current information suggests that the prevalence (current level) of chronic hepatitis C infection is around 0.4% of the general population (i.e. about 200,000 people in England).
- The incidence (new infection) of hepatitis C is not known, as the virus is usually acquired without symptoms and there are no laboratory assays to detect acute infections. However, there is evidence that the

incidence may be rising among injecting drug users.

- There is likely to be an increase in the diagnosis of hepatitis C in the next 10 years as individuals who have carried the virus for some time are identified through wider testing of groups who have been at risk.
- Some critics suggest that the prevalence in England is higher than the HPA's estimate, and there may be as many as 600,000 people infected. However, the evidence for this is not robust.

What is the prevalence of hepatitis C in other countries?

- The prevalence of the virus varies around the world and estimates of those who have been infected include around 1.6% of people in the United States, around 1% of people in France and around 3.0% of people in Italy. Other countries in the Middle East, Asia and Africa have much higher prevalence rates, notably Egypt where the prevalence is around 18%.

What is the current treatment for hepatitis C?

- NICE published recommendations in January 2004 on the use of combination therapy (pegylated interferon and ribavirin) for the treatment of moderate to severe chronic hepatitis C in adults. In August 2006, NICE extended these recommendations for the treatment of patients with mild chronic hepatitis C.
- The aims of treatment are to prevent progression to serious liver disease (cirrhosis and primary liver cancer). There is evidence that the treatment can clear the virus in between 45% to 85% of patients, depending on the virus genotype. The overall treatment success rate (i.e. all genotypes) is up to 55%.

Is there a vaccine to protect against hepatitis C?

- There is currently no vaccine to protect against hepatitis C infection, and one is unlikely in the near future. The virus is known to mutate (leading to a change in molecular structure) at a particularly rapid rate, which makes the development of an effective vaccine difficult. However, a number of centres around the world are involved in vaccine research.

B. Hepatitis C Action Plan for England

- The Chief Medical Officer highlighted the public health importance of hepatitis C in his infectious diseases strategy, *Getting Ahead of the Curve* in 2002. Later that year, the DH consulted on proposals to strengthen services for prevention, diagnosis and treatment and improve epidemiological surveillance and research (*Hepatitis C Strategy for England*).

- *Hepatitis C Action Plan for England*, published in 2004, sets out a framework of actions for DH, the NHS and other stakeholders such as the National Treatment Agency Substance Misuse and the Health Protection Agency (HPA) to tackle hepatitis C in four key areas:
 - Surveillance and research
 - Increasing awareness and detection of undiagnosed infections
 - High-quality health and social care services
 - Prevention
- DH is supporting implementation of the Action Plan by a centrally funded awareness campaign and improved epidemiological surveillance by the HPA. However, implementation and funding the Action Plan at the local level is the responsibility of NHS organisations and their partners

C. Awareness campaign

- The awareness campaign – branded *FaCe It* - is using a variety of communication methods to inform and influence healthcare professionals and the public. Campaign expenditure to date since 2003/2004 has been around £4 million, with anticipated expenditure in 2007/2008 about £2.75 million.
- It is encouraging that the awareness campaign appears to be leading to increased diagnosis of hepatitis C, which is one of its key aims. For example, there has been a significant annual increase in hepatitis C diagnoses in England reported to the Health Protection Agency through national surveillance over recent years.
- Research among GPs and practice nurses and the public indicates that awareness has increased since the campaign began but that more needs to be done. Therefore, the awareness campaign is continuing in 2007/2008 and will include further advertising.