PEOPLE LIVING WITH HEPATITIS C AND HIV
THEIR VIEWS ON WELFARE REFORM

Supported by

Terence Higgins Trust

Scottish Drugs Forum
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INTRODUCTION

Hepatitis Scotland and HIV Scotland recognise the economic, social and emotional problems associated with long term worklessness and the health benefits of employment related activity\(^1\). We support measures that have been taken in recent years to encourage and support people on longer term benefits to move towards readiness for work, such as Condition Management Programmes. However, we are very concerned that the impact of the Welfare Reform Act 2012 will have major implications and negative health effects for people living with Blood Borne Virus’ (BBV).

A significant proportion of people with blood borne viruses are dependent on state benefits for their basic living needs. People with long term conditions, especially Hepatitis C\(^2\) (HCV), are disproportionately located in areas in Scotland where there is low economic activity and growth and high levels of unemployment. More than half of the HCV diagnosed population reside in the most deprived fifth of the country.

Advances in treatment since the onset of the Human Immunodeficiency Virus (HIV) pandemic have enabled people to live longer and healthier lives. HIV is now treated as a chronic illness and defined as a disability from point of diagnosis under the Equalities Act 2001. Although these improvements have changed the lives of many, there remains large numbers of people living with HIV who have poor treatment responses and remain chronically unwell, both physiologically and psychologically.

After receiving numerous inquiries, regarding the welfare reforms from people affected by BBVs and services working with those affected, e.g. “Overall we dealt with 629 calls relating to benefits, as compared to 320 the previous year, a staggering 96% increase”\(^3\), Hepatitis Scotland and HIV Scotland used a series of nationwide events to gather evidence of the impacts the current reforms have had, and the likely effects of the reforms in line to be implemented.

\(^1\) Gordon Waddell and A Kim Burton (2006). Is work good for your health and well-being?
\(^2\) S. A. McDonald, S. J. Hutchison, P. R. Mills, S. M. Bird, C. Robertson, J. F. Dillon, A. Springbett and D. J. Goldberg (2010). Diagnosis of hepatitis C virus infection in Scotland’s injecting drug user population. Epidemiology and Infection, 138, pp 393-402 doi:10.1017/S0950268809990616
\(^3\) Hepatitis C Trust, May, 2012
Participation in these consultation events by people living with BBVs and agencies that work with people affected by BBVs highlighted key issues. We feel it is vitally important that these views of service users and agencies are taken into consideration.

This is a report of research undertaken to highlight the foreseeable negative effects the current and proposed welfare reforms are likely to have on people living with Hepatitis C and HIV. We have highlighted seven recommendations we believe are necessary to ensure the reforms are an improvement for people in Scotland and are not detrimental for people living with HIV and Hepatitis C.

Due to the nature of BBVs there is a need to look carefully at each individual case, recognising that the progress or treatment of a BBV is not a constant throughout the population nor indeed across each individual’s progression of their illness. It is also important to recognise the importance of early diagnosis and treatment as a key component in improving the fight against BBVs, which remains, for a significant minority, devastating and debilitating conditions.
**KEY FINDINGS AND RECOMMENDATIONS**

Key Findings were taken from survey data submitted by people who are affected by BBVs and who also attended the consultation events. These have informed achievable Recommendations, which can mitigate the impact of the proposed welfare changes.

89% of those surveyed have experience of paid employment. 77% stated they wanted to be in employment in the future.

No-one agreed that the changes would have an overall positive impact on their lives.

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**Quotes from respondents**

“I was not eating; lost all ability to do anything for myself, couldn’t walk, hallucinations, wet bed, and self harm. I was totally confused – I had to come off treatment”

“I couldn’t walk, never mind work”

“I went without money for 3 months, just to be put back on JSA, which left me destitute, begging, which was also detrimental to your health and well being. Left me in lots of debt to family and money lenders.”

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95% of survey respondents said their financial situation had negatively impacted their health.

42.5% said their financial situation had prevented them from accessing treatment

1. People living with certain symptoms of HIV⁴, or undergoing Hepatitis C treatment, should automatically be placed in the support group when applying for Employment Support Allowance, using the Exceptional Circumstances Rule.

2. Appropriate support for individual travel needs should be investigated for people undergoing or maintaining treatment and attending medical appointments for their BBV.

83% stated the welfare reform bill would have a negative impact on their lives. 13% stated they didn’t know what the impact would be, and 4% said there would be no change.

3. Due to changes in housing benefit, people living with a BBV who are aged 35 or younger may be forced to share accommodation with strangers. Due to the risk of involuntary disclosure of BBV status, and its attendant impact on the human rights of the affected person, possible measures to decrease the risk of disclosure should be investigated.

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⁴ E.g. with a CD4 count of less than 200, or who have stage 4 HIV infection.
4. Universal Credit should not be paid monthly but paid fortnightly in alignment with other benefits. All payments should be on an individual, not family basis. Means of maintaining direct payments to landlords should be investigated.

70% of those who had attended an ATOS Medical assessment did not agree with the decision they received. 100% subsequently appealed their decision.

80% stated their BBV gave them symptoms which made it difficult for them to work.

83% stated the treatment for their BBV gave them side effects which made it difficult for them to work.

5. DWP and ATOS staff should receive specialist training on Blood Borne Viruses, including symptoms and side effects of treatment.

6. The Work Capability Assessment (WCA) process is not fit for purpose. Measures must be taken to make it an evidence based-examination of current work capability.

7. DWP should immediately update their website on health conditions to include the latest evidence based material, especially for viral hepatitis. DWP must assess and update current guidance to GPs. DWP must provide a clear definition and guidance for staff as to what is meant by progressive and fluctuating conditions.

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The current extended wait for assessment of ESA benefits can have a destructive effect on those starting HCV treatment as the individual nature of treatment side effects means debilitating effects are not predictable in severity or when they occur. Timely access to benefits may be the difference between someone sustaining treatment or discontinuing, with possibly large social and cost consequences to individual and state.

Recent treatment advances for Hepatitis C have given hope for faster, more reliable treatment. However with new drugs have come a new range of variable, often intermittent side effects. Sustaining someone through now very expensive treatment requires an array of physical, social and mental health support. Putting this at risk through haphazard enforcement of the Work Capability Assessment is counter-intuitive and likely to cost much more to society in the longer term.

Furthermore, we are concerned that the assessment process for Personal Independence Payments (PIP) will not adequately take into account the nature of fluctuating conditions that people living with HIV experience, nor the myriad of potential side effects from HCV treatment. The new assessment does not fully recognise the health related barriers to work people living with these BBVs face; such as the side effects of treatment, depression, fatigue, diarrhoea, nausea and mental health problems. Nor does it address the social barrier of stigma and discrimination in finding work since HCV and HIV remain highly stigmatised conditions.

We are concerned that the referral process to specialist help is predicated on the subjective judgement of the DWP advisers and may be influenced by the relationship (or lack of) that exists between the customer and adviser. We ask that people living with BBVs be treated with fairness based on a good understanding of any long or short term medical conditions which may exist.
VIRAL HEPATITIS

Viral hepatitis is a disease which causes inflammation of the liver and can lead to serious illness and death if left untreated. It is estimated that around 39,000 people across Scotland are chronically affected by Hepatitis C - many of them unaware they are carrying the virus – while Hepatitis B infections are a growing cause of concern.

HEPATITIS C AFFECTS EVERYBODY DIFFERENTLY

HCV mainly affects the liver. When a liver becomes inflamed, it can become damaged and eventually have difficulty carrying out its various and vital functions. Over a long period of time, this can progress to serious liver damage (such as cirrhosis) or liver cancer in some people. Many people don't have any symptoms at all for the first 10-15 years, some for as many as 30 years. Others feel tired, depressed and have muscular and joint aches. Digestive, skin and memory problems have also been reported, as well as symptoms relating to the eyes and the thyroid. Generally symptoms are not related to how badly damaged the liver is. In other words, you can't tell the state of your liver by the state of your health. It is important to note that Hepatitis C affects people in different and unpredictable ways.

TREATMENT FOR HEPATITIS C

The current standard treatment for chronic HCV, commonly known as SOC or Standard of Care, is a combination of two drugs, Pegylated Interferon and Ribavirin. The length of treatment varies, depending on a number of factors.

GENOTYPE

There are a number of Genotypes of Hepatitis C, which affects the chances of treatment success. The main genotypes in Scotland are Genotypes 1 and 3. Using current SOC those with Genotype 1 have a less than 50% chance of clearing the virus while those with genotype 3 have a 60 to 70 percent chance of clearing the virus. Genotype 1 makes up roughly half of those diagnosed with HCV in Scotland.
SIDE EFFECTS OF PEGYLATED INTERFERON AND RIBAVIRIN

- Flu-like symptoms such as fever, chills, headache and muscle ache
- Fatigue or extreme tiredness.
- Nausea and loss of appetite are also common.
- Depression and related symptoms, such as anxiety, irritability, insomnia.
- Mental confusion and difficulty with concentration and memory.
- While less common, other psychiatric side effects include aggressive behaviour, psychosis, hallucinations, and mania; a few cases of suicide have been reported.
- Neutropenia, a blood disorder caused by a loss of white blood cells, puts people at risk for developing other infections.
- Colitis (inflammation of the colon) and pancreatitis (inflammation of the pancreas) may occur in some people.
- Anaemia, a blood disorder resulting in tiredness. After about two weeks of ribavirin treatment, about 10% of people develop a severe form of anaemia.
- Other side effects can include Alopecia (hair loss), Itchiness, Insomnia (having trouble sleeping), Arthralgia (joint pain), Myalgia (muscle pain) vision problems, and injection site reactions (soreness or swelling at the site of injection).

★★★★★★★★

Side effects are a common treatment experience however there is no standardised effect. Currently there is no proven way of predicting those who will be affected by side effects nor the degree to which they will experience those side effects.

★★★★★★★★
NEW TREATMENTS

Two new drugs, Telaprevir (Incivo) and Boceprevir (Victrelis) can now be used alongside SOC when someone is affected by genotype 1 HCV. They greatly increase the probability of someone clearing the virus through treatment. Neither Boceprevir nor Telaprevir reduce the side effects of Interferon or Ribavirin, and each comes with increased chances of different side effects. These include a much higher risk of anaemia or disabling rashes.

These two new drugs are extremely expensive and any treatment discontinuance is not only expensive, it can also increase the likelihood of drug resistance occurring. It is vital that those who commit to treatment have easier and early access to potentially treatment saving benefits.

★★★★★★★★★★

If there is a delay in access to ESA assessment there is a much higher likelihood of treatment discontinuation.

★★★★★★★★★★
**HIV**

HIV affects the body’s immune system by attacking the body’s defences against disease, making it less able to fight infections and more vulnerable to illnesses. Although there is no cure for HIV there is treatment available. A person living with HIV is said to be HIV positive. An estimated 5100 individuals are living with HIV in Scotland. Of these it is estimated 75% (3800) are diagnosed, with 25% (1300) remaining undiagnosed.

**HOW DOES HIV AFFECT THE BODY?**

HIV affects the body’s immune system by attacking the body’s defences against disease making it less able to fight infections and more vulnerable to illnesses.

Late diagnosis affects around half of all those who test positive for HIV. Many people living with HIV have to cope with the complications brought about by co-morbidities (more than one disease or disorder) to which they are susceptible because their immune system has been compromised. These include cardio-vascular, respiratory, cognitive, neuropathy and other health areas. If left untreated, HIV can cause AIDS (Acquired Immune Deficiency Syndrome). The term AIDS describes specific infections and illnesses resulting from the damage HIV does to the body’s immune system.

**TREATMENT AND SIDE EFFECTS**

Although there is no cure for HIV, medical treatment is available to slow down the spread of the virus in the body, and help people to live longer and healthier lives.

The combination of drugs that work against HIV, are called antiretroviral drugs (ARVs). ARVs work at reducing the amount of HIV in the blood to a level that is so low that it cannot be detected using standard viral load tests. This is called an ‘undetectable viral load’. Having an undetectable viral load means the immune system can recover its ability to fight off infections.

Patients tend to take three or more types of ARV medication. This is known as combination therapy or highly active antiretroviral therapy (HAART).
The following classes of anti HIV drugs are used for treating the infection:

- Nucleoside reverse transcriptase inhibitors (NRTI)
- Non-nucleoside reverse transcriptase inhibitors (NNRTI)
- Protease inhibitors (PI)
- Fusion and Entry inhibitors
- Integrase inhibitors.

Most people take a combination of two NRTIs and either an NNRTI or a protease inhibitor.

**SIDE EFFECTS**

Treatments have significantly improved the outlook for people living with HIV; however side effects of ART may be severe for some people. Common side effects include

- nausea
- tiredness
- diarrhoea
- skin rashes
- anaemia
- upset stomach
- loss of appetite
- mood changes.

A survey by NAT of people living with HIV found that HIV treatment was a cause of gastrointestinal problems in over 70% of people experiencing side-effects. HIV treatment is only effective if people living with HIV adhere to taking lifelong medications on time. Missing even a few doses increases the risk of the treatment not working. Many of the medications used to treat HIV can react in unpredictable ways if taken with other types of medicines.

★ ★ ★ ★ ★ ★ ★ ★ ★ ★

**People who are co-infected with HIV and Hepatitis C are susceptible to increased risks of side effects.**

★ ★ ★ ★ ★ ★ ★ ★ ★ ★
**WHAT WE DID**

Hepatitis Scotland and HIV Scotland, supported by Terrence Higgins Trust, hosted 10 Information Days throughout Scotland, between 21st February and 14th of March 2012. The timetable of events was:

- 21/02/2012 Glasgow
- 24/02/2012 Irvine
- 28/02/2012 Falkirk
- 29/02/2012 Glasgow
- 02/03/2012 Dundee
- 06/03/2012 Motherwell
- 08/03/2012 Aberdeen
- 09/03/2012 Inverness
- 13/03/2012 Edinburgh
- 14/03/2012 Dumfries
- 21/03 – 07/04 Online Survey

The Morning Information Sessions focused on explaining how people living Hepatitis B, Hepatitis C and HIV – Blood Borne Viruses (BBVs) - are likely to be affected by the welfare reform changes, whether or not they are in treatment. Patients, families and staff working with people affected by BBVs were all welcome to attend.

The afternoon session was a patients-only consultation event in 1:1 surveys, using trained peer researchers when available. It gave patients the chance to voice their concerns and experiences, allowing the three charities to hear more about the potential real-life impact of the changes. To allow people who either did not get the chance, or did not wish to attend the Information Days, we also created the survey in a web based format, and encouraged services throughout Scotland to support people to respond.
WHO WE SPOKE TO

We gave information to over 200 Patients, Family Members and Staff, informing them of the changes.

We gathered 55 staff opinions through a short confidential survey.

We gathered 44 patient opinions, either through 1:1s or online survey.

EVALUATIONS

Total evaluations received: 90

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<td>9%</td>
<td>26%</td>
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<td>66%</td>
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“Useful information, presented well, no jargon and easy to follow”

“I feel a little more placed to support clients in benefit applications”.

“Very useful information! Great to know about future changes to start preparing people”.

“Pity my whole team could not attend, will attempt to feedback most important points”.

SURVEY OF THOSE LIVING WITH HIV OR HEP C

People were invited to take part that were living with a BBV and had experience of receiving benefits.

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<td>HCV – had treatment no response</td>
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<tr>
<td>HCV – had to stop treatment</td>
<td>1</td>
</tr>
<tr>
<td>HCV – not received treatment</td>
<td>8</td>
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<td>HCV – on treatment</td>
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<table>
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<td>HIV – on treatment</td>
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<td>Employed Part Time</td>
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<tr>
<td>Retired</td>
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<td>Unable to Work</td>
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*People could choose all that applied.

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<tr>
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<tr>
<td>Disability Living Allowance</td>
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<tr>
<td>Housing Benefit</td>
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<tr>
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</table>

*People could choose all that applied.
EXPERIENCE OF THOSE AFFECTED BY BBVs

The following results, quotes and statistics reflect the views and opinions of people we surveyed. People opted to take part in the survey based on their BBV status, and their concerns/personal experience of claiming benefits.

FINANCIAL SITUATION IMPACT ON HEALTH

95% of respondents said their financial situation had adversely impacted upon their health.

MENTAL HEALTH

13 respondents stated their financial situation had impacted their mental health. This included stress: 7, depression 6, and 2 stated they had had suicidal thoughts due to lack of financial resources.

“Stress, mental health, I have felt suicidal. If anything breaks down I have no money”

“Depressed, unable to care for problems with mental health because of pressure with bills”

TRAVEL

17 (42.5%) respondents said they had missed medical appointments because they could not afford the bus fares. 4 stated they had not missed appointments, but this was due to either having a bus pass or being within walking distance of appointments.

“Travel costs to pick up daily medication, gas and electric, food and clothing – all of this cost more than I receive!”

“Missed lots of appointments as I can’t afford this”

One respondent we spoke with, living in a rural community, pays £5.25 in bus fares for each medical or DWP appointment. He receives £67 per week, and can often have 2-3 different appointments a week. This can be between 15 and 25% of weekly income on travelling to benefits or health related appointments.
Food

15 respondents said they could not afford to eat healthily as recommended by medical professionals.

“Feeling really low, stress, down on myself, I can’t eat healthily”

One respondent stated they were hospitalised for malnutrition and that this was due to not having enough money to buy food.

Heating

20 respondents said they often went without heating. Electricity and Gas seemed to be the first commodity people would ‘go without’. Other things people said they went without included; toiletries, social life, holidays, haircuts and vitamins.

“Electricity costs too much – budget that with childcare and food - very difficult to manage”

Budgeting

We asked respondents if they felt received enough money to adequately live on while suffering affects of a BBV.

47% said they didn’t receive enough money, 14% said their money was ‘sometimes’ enough, and 39% stated the money they received was enough to live on.

“I try and budget but I’m always left with no money. I’m usually left with no money on Sunday, and get money on Tuesday.”

“I make it last, stock up the freezer, then energy bills, if I didn’t have a bus pass, I would not cope - I got this through mental health”

“Not always, depends on the number of appointments per week”
**EMPLOYMENT**

89% of respondents said they had previous employment history.

77% (n=35) stated they aspired to work in the future, when they felt well, ready, and supported. 17% were unsure of their future aspirations. Only 2 stated they had no aspirations to work in the future.

80% of respondents said that their BBV gave them symptoms which made it difficult for them to work. Symptoms included:

- lack of energy
- mental health / depression
- other non physical symptoms including anxiety, listlessness, brain fog and insomnia

83% of respondents stated that the treatment for their BBV gave them side effects which made it difficult for them to work. Side effects included:

- anaemia
- mental health including depression, anxiety and suicidal tendencies
- Other physical side effects including diarrhoea, pain in legs, musculoskeletal disorder.

“while on treatment it would have been impossible to work”

“I was not eating; had lost all ability to do anything for myself, couldn’t walk, had hallucinations, wet the bed, and self harm. I was totally confused – I had to come off treatment”

“I couldn’t walk, never mind work”
22 of 34 question responders stated that both their blood borne virus and the treatment for their blood borne virus had an impact on their ability to work.

“right now I don’t think I’m physically and mentally ready for work, but I do aspire to seek qualifications in the future for work in the care field.”

When asked what support would improve their chances of entering employment the following was observed:

- 48% stated training and education
- 30% stated confidence building
- 30% stated improved health
- 30% stated having employers who understood their condition
- 26% stated better support from professionals

“next time at interview, ......., I will ask how they feel about employing someone with HIV and mental health history - if they don’t want me it’s their problem, I don’t want to work for them.”
9 respondents had to go to the Jobcentre on a regular basis. The majority were on ESA, Incapacity or assessment benefits. They were asked to rate DWP staff on their knowledge of blood borne viruses, from 1-5.

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<thead>
<tr>
<th>No Understanding</th>
<th>Excellent Understanding</th>
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<td>4 2 1 2 0</td>
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DWP’s information on BBV’s was assessed for currency. The information lacked sufficient detail, was not up to date and potentially favoured being found ‘fit for work’ by making assumptions that do not appear to be evidence based.

“....resultant care needs or difficulties in walking attributable to drug side effects such as fatigue, flu like symptoms etc. should be carefully evaluated. In many cases they will not be sufficiently severe to affect personal care or to restrict mobility and will only persist for the limited duration of the treatment.”

Terrence Higgins Trust offered to provide DWP staff with free training on blood borne viruses’. This offer was not taken up.

DWP STAFF ATTITUDE

<table>
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<th>Poor Attitude</th>
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<tbody>
<tr>
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<td>6 4 1 1 2 7</td>
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“Only spent 10 minutes with me, so difficult to tell”    “Looked down on me.”

“No stigma shown”

http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions/viral-hepatitis-hepatitis-a-b/
**DWP Staff Understanding**

21 of the respondents had received a work capability assessment.

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<th>Excellent Understanding</th>
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“They have no knowledge at all of hep c, and its symptoms”

“They never asked any questions, only asked if I could lift a pot and lift my legs. Left completely bamboozled - mental health and hep c not mentioned”,

“At the first assessment hep c & treatment was recognised but at the second assessment post treatment side effects were not taken into account, like my worsening depression”

**DWP Assessment Met Their Needs**

14 of the 21 respondents answered the question “Did the assessment accurately reflect your needs?” 8 said No.

“I spoke to her at length about my hep c but felt she was not listening to a word I said”

“Not at all”

“can you pick a 20p piece up?”

“Questions specific to my disability, assessor asked about side effects of HIV treatment.”

**Decision**

17 respondents received a decision from ATOS/DWP on their medical. 70% (12) did not agree with the decision they received.

“its nuts, a joke, expecting too much, people deemed unfit by GP then told they’re fit for work”
APPEAL

All 12 respondents who did not agree with their decision appealed against it:

- 58% were successful in their appeal
- 17% are awaiting their decision
- 25% people were unsuccessful in their appeal.

“I went without money for 3 months, just to be put back on JSA, which left me destitute, begging, which was also detrimental to your health and well being. Left me in lots of debt to family and money lenders.”

DWP GUIDANCE

“A short guide to the benefit system for General Practitioners”, issued by the DWP, states:

“Your patient may need Med3s if they are appealing a benefit decision and want to claim Employment and Support Allowance until their appeal is heard ....... If you choose not to issue a Med3, your patient will in most cases be able to claim Jobseeker’s Allowance during the appeal.” “If the appeal is unsuccessful, you should only issue further Med3s if their condition worsens significantly or they have a new medical condition.”

A GP that feels a patient is unfit for work would be at odds with their GMC code of conduct if they altered their opinion due to outside pressure. It is concerning that the choice of wording in the guidance could be easily misinterpreted as a direction to find patients fit.

A recent 2012 Scottish GP Conference called for the Work Capability Assessments to be abolished and replaced with a safer, more vigorous, process. Dr Andrew McNutt said:

“There has been a dramatic increase in the numbers being assessed as fit to work and a massive number of appeals have been made against these decisions. These assessments can have a devastating effect on our patients' mental and physical health”.

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6 Scrap Work Capability Assessments, say GPs (BMA Scotland Thursday 22 Mar 2012)
WORK CAPABILITY ASSESSMENT

What training do doctors, nurses and physiotherapists receive? For the Work Capability Assessment, this includes an up to eight day course for doctors and up to 17 days for nurses and physiotherapists. Training of these professionals is in three distinct areas:

- Generic training
- Training to undertake benefit-specific assessments
- Scrutiny and file work training.

Terrence Higgins Trust offered to provide DWP staff with free training on blood borne viruses'. This offer was not taken up.

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PERCEIVED IMPACTS

The following results, quotes and statistics reflect the views and opinions of people we surveyed. People opted to take part in the survey based on their BBV status, and their concerns/personal experience of claiming benefits.

CONTRIBUTORY EMPLOYMENT SUPPORT ALLOWANCE

Contributory Employment Support Allowance (if you have paid enough NI contributions this is non–means tested) for people in the Work Related Activity Group, is time limited to 12 months from April 2012, retrospective.

16 people (out of 37 responses) stated that they felt they would be impacted by ESA being means tested after 12 months. 4 people were unsure, and 17 people felt they would not be affected.

“I don’t know how long I will need physio and meds; I suffer from depression and anxiety which have remained from treatment”

“I’m single, scared to get into a relationship as my benefits could be affected.”

“Take into account the varying nature of living with a long term viral condition. It tires you out and affects your mental health.”
**Universal Credit**

Universal Credit is due to be introduced for new claimants from October 2013, with planned migration for current benefit recipients up until 2017. Universal Credit will combine all means tested benefits (*JSA, ESA, Housing Benefit, Income Support, Incapacity Benefit, and Tax Credits*). Currently, it is envisaged that Universal Credit will be paid **monthly**, in arrears, to one member of the household (either the single benefit recipient, or one person within a couple).

We asked respondents what they felt the best timeframe for receiving benefits was. There were 36 responses to this question:

- 21 people stated weekly payments are easier to manage.
- 10 people stated it should be kept fortnightly, as people are used to it.
- 4 people thought monthly payments would make it easier for them to manage their direct debits.
- 1 person stated ‘other’ and went on to explain that people should be able to choose the frequency that works best for them.

“I struggle to budget fortnightly and would find it impossible if monthly”

“Mental health and addictions - will be a disaster if it’s monthly.”

“Paid monthly is unacceptable. Nothing good can come from it.”
**HOUSING BENEFIT CHANGES**

From January 2012 changes to Housing benefit affected Local Housing Allowance – the Housing Benefit paid for private rented tenancies. Since January 2012 single people without dependants aged 25-34 entitled to Local Housing Allowance (LHA) have had their benefit restricted to rent for a room in shared accommodation. Previously the shared room rate applied to single people under the age of 25.

The reduction in LHA entitlement is, for example, from £108 per week for 1 bedroom to £68 per week for shared accommodation in Lothian. The majority of those affected will not be able to afford their present accommodation and will either have to seek alternative shared accommodation, make other arrangements or make a homelessness application. Some BBV treatments need to be refrigerated, and in doing so, people on treatment will not only be inadvertently disclosing their health condition to flatmates, some of who may be strangers, but will also have to risk their medication being safe and secure within a shared house.

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There are strong concerns over the disclosure of peoples BBV status when forced into shared accommodation. The supply and demand for shared accommodation in Scotland may have profound implications for people living with BBVs.

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WHAT STAFF THOUGHT

55 Staff gave their opinion on Welfare Reforms.

<table>
<thead>
<tr>
<th>Role</th>
<th>Response</th>
<th>Sector</th>
<th>Response</th>
<th>Main Client Group</th>
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</thead>
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<tr>
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<td>44</td>
<td>Voluntary</td>
<td>21</td>
<td>BBV</td>
<td>14</td>
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<tr>
<td>Policy</td>
<td>2</td>
<td>Social Work</td>
<td>12</td>
<td>Addiction</td>
<td>16</td>
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<td>Manager</td>
<td>6</td>
<td>Health</td>
<td>10</td>
<td>Homelessness</td>
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<td>3</td>
<td>Other</td>
<td>12</td>
<td>Other</td>
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Surveyed staff were unanimous in condemning the negative effects of the benefit changes and the impact upon service users, expressing frustration and dismay with the effect of the changes which will in many cases lead to poverty, increased financial hardship and homelessness. Of particular concern was the sense that service users and clients would be prone to worsening mental health as a result of increased stress, anxiety and confusion due to the changes and that any mental health issues would not be properly addressed in Personal Independence Payment (PIP) assessment.

Staff were concerned at the knock-on effect in dealing with increased workloads, especially to overstretched organizations such as Citizens Advice Bureau, resulting in less time to spend dealing with other client enquiries. Staff felt that the complexity of the benefits changes would cause frustration and desperation among service users, thereby increasing criminal activity. A nurse working with drug users between 16 and 65 commented that:

"The reforms will have a destructive impact on treatment of clients who are already at disadvantage in society. Clients who are drug users are being encouraged to come and participate in treatment, for example, methadone. This treatment relies partly on the stability of social circumstances to be partially/totally successful, as is Hepatitis C treatment. The impact the reform bill will have on our clients, who are already chaotic, is they will find it difficult to access money from benefits and therefore it will create a worse off population"
The effects of the changes on housing benefit were of particular concern to staff surveyed. A frontline worker who supports people to gain a tenancy in Falkirk stated:

“People with mental health problems not coping with the changes - not applying for new benefit. Housing benefit changes could cause massive implications - people not forwarding housing benefit to landlord resulting in more homeless people”.

A common theme emerging from the results of the survey was the connection between poverty, debt, the prospect of becoming homeless and the mental health and wellbeing of service users. A number of staff had already encountered service users who were experiencing worsening physical health and mental health due to the stress and worry in surviving on little money. Staff fear there will now be no safety net to protect these vulnerable people.

“It is already impacting on peoples mental health - the fear of attending medicals has increased my workload significantly. People will be confused and worried by the changes”

The mooted monthly benefit payments were seen as also potentially having a seriously debilitating effect on clients due to a lack of budgeting skills and the impact of substance use issues.

“monthly benefits would be highly detrimental to those with drug/alcohol addictions”

Some staff stated that many service users would be unaware of the changes with benefits being stopped and have no one to assist with appeals against benefit decisions.

“reform is more concerned about cutting costs than peoples welfare.... whole focus of the reform is to save money and not to support those in crisis or most vulnerable in society”
CONCLUSION

HIV has some protected status as a long term, fluctuating health condition. The Equality Act 2010 states:

“A person who has a progressive condition, will be treated as having an impairment which has a substantial adverse effect from the moment any impairment resulting from that condition first has some adverse effect on his or her ability to carry out normal day-to-day activities, provided that in the future the adverse effect is likely to become substantial”

“The Act provides for a person with one of the progressive conditions of cancer, HIV and multiple sclerosis to be a disabled person from the point at which they have that condition, so effectively from diagnosis” \(^\text{10}\)

Due to the range of debilitating side effects associated with HCV and HBV treatment there is a strong case to be made for people with viral hepatitis to also be automatically placed within the support group for Employment Support Allowance, using the Exceptional Circumstances rule – which states: “claimant suffers from disease or bodily or mental disability and by reasons of these there would be a substantial risk to the mental or physical health of any person if claimant were found not to have a limited capability for work”

Reasons include:

- It allows people to focus on improving their health.
- It removes the barrier to treatment regarding the fear of side effects making them unable to work.
- Being financially able to support oneself reduces stress.
- Increased appointment attendance due to reduced stress, increased financial security and the ability to focus on personal health as opposed to undertaking work related activity.
- GPs and other medical professionals have agreed that the person should not work.

\(^\text{10}\) Equality Act 2010
Treatment side effects are not predictable and can be extremely debilitating. The economic and societal cost of discontinuing treatment far outweighs the costs of automatic support group placement.

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Treatment for Hepatitis C ranges from 3 – 12 months, while waiting times for decisions and appeals currently take the same length of time. Due to current waiting times both for the medical assessment from ATOS and then a decision from the DWP, and in many cases then waiting for appeal an eligible person may have finished or even dropped out of HCV treatment before any decision is made.

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However well intentioned the welfare reforms are there is little doubt that they have the capacity to cause immense hardship to vulnerable people who have long term medical conditions and who are already struggling to subsist on limited amounts of money.

People with HIV and Hepatitis C often have symptoms of their condition, as well as side effects from their treatment regime, which are not taken into account at their work capability assessment. They also face additional stigma discrimination, prejudice and negative attitudes as a result of ignorance and misconceptions.

The main risk factor for Hepatitis C is injecting drug use. 90% of people in Scotland are thought to have become infected with hepatitis C through this transmission route.

The main risk factors for contracting HIV are through having unprotected anal and unprotected vaginal intercourse. High prevalence rates of HIV are found in gay men and other men who have sex with men, and in people originating from African Countries.

According to a recent report from the Disability Rights Commission 38% of employers would not employ anyone with a history of mental health problems and a Chartered
Institute of Personnel and Development report\textsuperscript{11} found that a third of employers would deliberately exclude people with a history of long term sickness or incapacity when recruiting staff. In a Scottish study people on methadone came at the top of a list of ‘hard to employ’ categories with over 70% of employers saying they would not employ people from that group\textsuperscript{12}.

The vast majority of employers are reluctant to employ someone who is likely to be taking erratic and potentially extensive periods of sick leave, or having to change working hours/duties, sometimes significantly and at short notice, due to the fluctuating nature of their illness. Employers may be sympathetic to the problems that people with BBV’s face however the impact of a person’s level of ill health and/or disability will be an unattractive proposition for many employers in terms of recruitment and employment, and especially when there is such a competitive employment market.

\textbf{CLOSING STATEMENT}

This document reinforces other recent social research in this area by demonstrating that the impact of these current, and proposed, welfare benefits changes are likely to be overwhelmingly negative amongst people affected by blood borne viruses.

Those affected by viral hepatitis and/or HIV are often very marginalized and stigmatized members of our society. Even if appropriately assessed as fit for work, they are highly unlikely to easily access employment. Their prospects of overcoming their illness, whether physically or mentally, can be significantly determined by financial hardship. Spending large amounts of public monies on healthcare in this area, as per current Scottish Government policy, then directly contradicting it by imposing benefits changes that are likely to disproportionally impact on people living with BBVs appears at odds with the professed policy goals of the UK Government.

\footnotesize{\textsuperscript{11} Incapacity benefit reform: Why it is needed and how to engage employers, 2006
APPENDIX: BENEFITS UPDATE FOR CLAIMANTS

by Terrence Higgins Trust

There are major changes happening to welfare benefits at the moment, some of which are in the process of being implemented, but there are more to come that will totally change the benefit system as we know it.

WHAT’S HAPPENING NOW

EMPLOYMENT SUPPORT ALLOWANCE (ESA)

ESA is the benefit brought in by the last Labour government to replace Incapacity Benefit (IB) and Income Support for reasons of incapacity for work (IS).

The aim of introducing ESA was to reduce the number of people claiming IB/IS by around 50%. Originally it was just for new claimants, but from March 2011 those who already had a claim for IB/IS started to be migrated to the new benefit. This is ongoing and the government hopes to have finished the process by April 2014.

The process of migration should happen as follows:

1. the claimant will receive a phone call from the Department of Work and Pensions to tell them that they are due to be reassessed for ESA and that they will shortly receive a form through the post which they must fill in and send back by the date stated in the accompanying letter or risk losing benefit.

2. The form, an ESA50 or Limited Capability for Work questionnaire as it is known, should then arrive in the following weeks and needs to be returned within four weeks.

3. One of two things will then happen: either the person will be accepted onto ESA (and placed into one of two groups – more on that later) or will be asked to attend a medical assessment if the DWP do not feel that they have enough information.

There are a few important points to do with this process that claimants should be aware of. Firstly, when you get the form, please make a note of the date that it has to be returned by and don’t be fooled by the box at the end that says “tell us why you are returning this form late”. If you return the form after the date on the letter then your benefits may well be cut and it can take some time to get them back in payment. You can no longer phone and ask for an extension to return the form. You should put in as much detail as possible on the form – try not to just tick the boxes, explain why you can’t do things and what difficulties you have. Remember that it’s better to write too much than too little.

Secondly, if you are called to a medical assessment you should try and take somebody in with you and to make notes, you should know that you have the right to do this. The reason for doing this is a) to try and make sure that the EMP is doing their job properly, and b) should your claim go to appeal then it helps if you have a witness that can verify that the
assessments was not accurate. Many people find that when they get their appeal papers through that the medical report bears little resemblance to what was actually discussed during the assessment.

Should you be successfully transferred to ESA then you will be placed either in the work related activity group (WRAG) if the assessor feels that you would benefit from a phased return to work, or the support group if you are unable to carry out any kind of work. You can appeal a decision that you should be in the WRAG.

Should you be refused ESA and you disagree with the decision you can lodge an appeal, but you will need medical certificates from your GP whilst you wait the hearing. For more information about appeals please talk to an adviser. You can contact Terrence Higgins Trust for more information about this.

Contributions Based ESA (CESA) replaces Incapacity Benefit. You can claim this if you have paid enough National Insurance contributions. The key fact about this is that it is not means tested, but if you are placed in the WRAG you can only claim CESA for 12 months – after that it will be means tested. Therefore if you have a partner who works or if you have more than £16000 in savings then you will not be eligible for benefit. Again, if you feel that you should be in the support group you can appeal the decision to place you in the WRAG within one month of the decision letter.

**TAX CREDITS**

There have been numerous changes to tax credits over the past year or so. The headlines are that you have less time to inform HMRC of any changes to your circumstances, most tax credits have been frozen, and fewer people will be entitled.

One change that affects couples with children is that they now have to work a minimum of 24 hours a week, with one member of the couple working at least 16 hours. This coupled with the fact that the baby addition has been scrapped and that child care contributions have decreased from 80% to 70% is particularly harsh for parents on low incomes who are trying to work to get out of the benefits trap. Basically if you have one child and earn more than £26000 then you will not receive child tax credit, and if you have two or more children then that figure is £32000. You may still receive something towards childcare costs.

**HOUSING BENEFIT**

The recent changes to Housing Benefit (HB) only affect Local Housing Allowance (LHA), i.e., those renting in the private sector, but be warned, that some of the same changes will be brought in to public sector housing next year.

LHA is now set at the 30th centile of the broad market rent. This means that in any one area, only the cheapest 30% will be available to those claiming HB. Previously, LHA was set at the
midpoint of rents in an area, so that 50% of the houses would be available to those claiming HB.

It used to be that if you were under 25, single and had no dependants, then you could not claim HB for a house in your own right. This now applies to anyone under the age of 35, unless that person has the need for a carer and in receipt of DLA at the middle rate of care. This doesn’t apply to single parents who have their children living with them, but it does apply to parents who do not have care of their children.

Non dependant deductions have increased: this is the money that is taken off your HB for anyone who is staying with you who is not a dependant, e.g. a child over the age of 18, a friend you may have taken in to help them out of a tight spot etc. The person who is the non dependant is expected to make up the short fall in the rent, but this rarely happens in our experience, and it is the tenant who ends up paying.

From April 2013, all HB claimants, including those in social housing, who are of working age, will be restricted to the number of rooms “needed”. This means that if, for example, you have a spare room that you currently use because your disabled partner can’t always sleep well then you will lose some housing benefit.

**OTHER BENEFITS**

The Maternity Grant is paid to women on a low income: it used to be that all children born to low income families used to be eligible for up to £500. This has now been restricted to the first child only. Child Benefit has been frozen for the next three years, and higher income families are not longer entitled to CB.

Possibly the only bit of good news is that state pensions will be increasing, as will Pension Credit, and that they will continue to increase in line with the Retail Price Index (RPI). However all other benefits will be linked to the Consumer Price Index (CPI) which is a lower rate than the RPI. At the time of writing the RPI was 3.6%, which is lower than usual, and the CPI was 3.5%. This may not seem a lot, but the government has calculated that this will be where their greatest savings will be made over the next 5 years.
**WHAT’S TO COME?**

There will be two major changes to benefits starting in 2013. The first is that Disability Living Allowance (DLA) will start to be scrapped and Personal Independence Payments (PIP) will be brought in to replace it.

We know a fair amount about what PIP will look like, for example, we know that it will be a points based system and that all applicants will have to undergo a medical assessment. There are drafts of the descriptors and points awarded out at the moment on the DWP website: these may change, but if anything they are only likely to be tweaked. There are still consultations to be done with regard to PIP and we urge people to keep an eye out for these and to give their views.

PIP will be up and running for new claimant from April 2013 and the migration from DLA will start later that year.

The biggest change of all though is the introduction of Universal Credit in October 2013. Universal Credit will incorporate all means tested benefits for working age people including Housing Benefit, Tax Credits, Job Seekers Allowance, Employment Support Allowance, Income support and so on. Again we know some information about Universal Credit, but many of the details are still being decided upon. What we do know is that the government are proposing to migrate all claims by October 2017, it will be paid monthly to one claimant in the household, and there will be no disability elements as there are with JSA/IS/ESA at present. The government have promised that no one will be worse off when they change to the new benefit, but the reality is that year on year, all benefits will be worth less than they are at present.
Hepatitis Scotland was launched in 2011, hosted within Scottish Drugs Forum and funded by the Scottish Government to lead the voluntary sector input towards improving the prevention, treatment and support for viral hepatitis. It works towards preventing the spread of viral hepatitis through the highly infectious Hepatitis B and C viruses; increase the numbers of people diagnosed with viral hepatitis; improve access to hepatitis treatment and support; improve the range and quality of prevention, treatment and care services and reduce stigma associated with viral hepatitis.

HIV Scotland is the national HIV policy charity for Scotland to help inform and deliver strong policies and effective strategies on HIV and related issues. It provides expert advice and a voice for HIV in Scotland; information, training and resources; signposting to evidence, expertise and community experience; opportunities to engage with others in shaping policy and practice.

Terrence Higgins Trust is the UK’s largest HIV and sexual health charity, with centres across Scotland, England and Wales. It provides information and advice about HIV and sexual health and offers a range of services including sexual health checks, counselling and support groups.

Scottish Drugs Forum is a membership-based drugs policy and information organisation and is a national resource of expertise on drug issues.
We would like to thank everyone who participated in the events, especially to those people living with hepatitis C and HIV whose generosity in sharing their lived experiences enables this research to inform policy development that can improve the health and wellbeing of all people in the community. Thanks also to the research team who worked long flexible hours to pull these stories together from all across the country.