

# AIDS & HEPATITIS Digest

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## Living Well's Positive Self-Management Programme for people living with HIV

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In the not too distant past, HIV infection resulted in progressive immunosuppression, increasing ill health and the advent of pre-terminal AIDS-defining infections and cancers. But as a result of dramatic developments in antiretroviral therapy since the early 1990s, HIV infection in the developed world has been transformed into a manageable chronic disease. This is presenting new challenges to those living with HIV as the focus increasingly moves away from coping with serious illness and premature death and to successfully managing a chronic medical condition. Living Well's Positive Self-Management Programme (PSMP) helps people to meet these challenges by enabling them to maintain their independence while increasing their confidence and skills, and maximizing their quality of life.

Funded by the National Health Service (NHS), Living Well is one of the core health care initiatives being offered across London to people living with HIV. It provides a wide range of services that:

- promote life skills;
- encourage the development of a supportive social community;
- empower participants with the ability to self-manage their condition.

This article discusses the concept of patient self-management programmes for people living with chronic conditions. It examines the origins, structure and objectives of the Expert Patients Programme (EPP) and the PSMP, and summarizes the findings from Thames Valley University's three-year evaluation (2005–08) of Living Well's new version of the PSMP.

### Background

Chronic illness presents a significant cost burden for the UK economy and the NHS.<sup>1</sup> Collectively, incurable and long-lasting health conditions currently cost the UK around £12 billion a year in disease management and lost earnings.<sup>2</sup> On a more personal level, managing chronic conditions such as HIV and hepatitis can be a complex, time-consuming and challenging process.<sup>3</sup> However, because of the nature of long-term illness, it is often the patients (rather than health care professionals) who are responsible for the routine management of their day-to-day



physical, psychological and emotional health. This 'self-management' will often involve:

**[all] the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions.**<sup>4</sup>

Many of the problems will be specific to the patient's illness, but there is also a core of common tasks that all patients will be asked to perform. These include:

- closely monitoring their symptoms and responding with appropriate actions;
- dealing with acute attacks or exacerbations of the disease;
- making major lifestyle changes;
- dealing with fatigue;
- adhering to intricate medication and treatment regimens;
- attending clinic visits for tests, physical examinations and consultations;
- managing work;
- developing strategies to deal with the social and psychological consequences of the illness.<sup>5</sup>

### Patient self-management programmes

Patients often have difficulty performing many of these tasks and most will need help and encouragement to perform them successfully and to engage effectively with the maintenance of their own health.<sup>3</sup> Traditionally, patients in the UK have not received this type of support from health care providers in the NHS, the social services or the employment services, and their self-management needs have largely been ignored.<sup>5</sup> However, the emphasis has shifted and patients are now viewed as key decision-makers in the treatment process:

**By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. Self-management programmes can be specifically designed to reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy.**<sup>5</sup>

For this reason, new educational health programmes that help people to manage their conditions have recently been developed, in recognition of the fact that treating chronic illness requires a new model of care, in which patient self-management plays a fundamental role.<sup>3</sup> These new 'self-management programmes' are designed to educate and support patients while increasing their skills and confidence in managing their health-related problems and improving their overall quality of life. In these programmes, patients are taught how to monitor symptoms, set goals and solve problems, while being encouraged to work collaboratively with their health care team and to take advantage of the supportive services available to them.

The concept of patient self-management was first developed in the 1960s and 1970s as a method

of seeking better solutions to illness. Today, self-management is seen as an integral, even central, part of the system of care provided to people with chronic diseases.<sup>6</sup> Patient self-management programmes are not simply about educating patients or giving them relevant information – they are based on developing patients' confidence, motivation and ability to take effective control over life with a chronic condition.<sup>5</sup>

Regardless of whichever chronic condition a patient may have, the aim of all self-management programmes is to change behaviour. Successful programmes are those that are able to motivate their participants to make positive and meaningful improvements to the way they manage their lives. They do this using a variety of methods, but fundamentally they foster change by increasing knowledge, motivation and confidence, and enhancing self-belief and self-efficacy. This should, in turn, translate into better patient outcomes and reductions in patients' use of health care services, particularly preventable consultations with general practitioners (GPs), visits to accident and emergency departments and hospitalisations.<sup>3</sup> In this way, self-management programmes should benefit the state, commerce and the individual, by reducing the need for costly health interventions, reducing days off work and generally improving health outcomes for chronically ill patients.<sup>3</sup> The pivotal objective of the self-management programme, however, is to empower individuals by enhancing their ability to take full control of their lives.

### User-led initiatives and the Expert Patients Programme

User-led self-management programmes were pioneered by Professor Kate Lorig of the Patient Education Research Center at Stanford University, California, USA.<sup>7</sup> In the 1970s, Lorig produced an initial practical approach to self-care; in the 1980s, this was revised to take into account work on social learning done by Albert Bandura, Stanford Professor of Social Psychology.<sup>7</sup>

The first courses were based on the experiences of people living with arthritis and recognized that people with chronic conditions have to deal with common issues on a daily basis. These training programmes eventually evolved into Stanford University's present Chronic Disease Self-Management Program (CDSMP), a highly structured, scripted series of workshops, each of two and a half hours, delivered once a week, for six weeks, in community settings by trained volunteers, all of whom are themselves living with a long-term condition. Subjects covered include:

- techniques to deal with problems such as frustration, fatigue, pain and isolation;
- appropriate exercise for maintaining and improving strength, flexibility and endurance;
- appropriate use of medications;
- communicating effectively with family, friends and health professionals;
- nutrition;
- how to evaluate new treatments.<sup>8</sup>

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A key element of the programme is its use of trained lay people with chronic illness as tutors. According to Stanford University:

**It is the process in which the program is taught that makes it effective. Classes are highly participative, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active and fulfilling lives.<sup>8</sup>**

## Self-management programmes in the UK

Following the success of Stanford's CDSMP, a number of similar self-management programmes were developed by patient groups and representative organizations in the UK.<sup>5</sup> Examples include: Arthritis Care's Arthritis Self-Management Course (ASMC) and the Multiple Sclerosis Society's Self-Management Course, both of which are based on the Lorig model; and the Manic Depression Fellowship's Self-Management Training Programme (SMTP). In the UK, as elsewhere, these types of lay-led programmes proved to be 'an effective way of training people with long-term conditions to take an active role in the management of their lives'.<sup>7</sup>

The 1999 White Paper *Saving Lives – Our Healthier Nation* recognized the effectiveness of self-management training courses and acknowledged that more support needed to be given to patients living with long-term chronic conditions. Recognition of the national importance of self-management programmes was then reaffirmed in 2000 by *The NHS Plan*, but it was not until the release of the Department of Health's 2001 report *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century* that government officially recommended the creation of a new NHS-based self-management training programme for patients living with long-term conditions. It was on the back of this recommendation that the current Expert Patients Programme (EPP) was created.

Closely based on Stanford's CDSMP, the EPP is a six-week course comprising six two-and-a-half-hour workshops. Each week, two lay volunteer tutors, who are also living with a long-term health condition, lead

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8–16 participants through structured course material delivered from a scripted manual. The topics covered included relaxation, diet, exercise, fatigue, breaking the symptom cycle, managing pain and medication, and communication with health care professionals.<sup>6</sup> The principal aim of the EPP is:

**to give people the confidence to take more responsibility and self-manage their health, while encouraging them to work collaboratively with health and social care professionals.<sup>9</sup>**

Evaluation data from approximately 1000 course questionnaires have shown that, four to six months after completing the course, for the participants:<sup>9</sup>

- GP consultations had decreased by 7%;
- outpatient visits had decreased by 10%;
- attendances at accident and emergency departments had decreased by 16%;
- pharmacy visits had increased by 18%.

In addition to this, key research findings from a randomized trial carried out by the National Primary Care Research and Development Centre<sup>9</sup> found that course participants have:

- improved partnerships with doctors;
- increased confidence to manage their condition;
- improved quality of life and psychological wellbeing;
- increased energy;
- high satisfaction with the course.

Given the success of the EPP initiative, the UK government has further strengthened the commitment to patient self-management through policy documents such as *Supporting People with Long Term Conditions: An*

NHS and Social Care Model to Support Local Innovation and Integration (2005), *Self Care – A Real Choice: Self Care Support – A Practical Option* (2005), and *Our Health, Our Care, Our Say* (White Paper, 2006). Furthermore, in April 2007 the EPP was established as a Community Interest Company (EPP CIC) to expand the work already undertaken across England. The aim is to increase EPP capacity from 12,000 course places a year to over 100,000 by 2012.<sup>9</sup>

### The Positive Self-Management Programme (PSMP)

The EPP has proven effective at creating a cadre of ‘expert patients’, defined as:

people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases and to minimise the impact of disease on their lives.<sup>5</sup>

It does, however, take an extremely generic approach to self-management and does not provide any specific health information or treatment; nor does it address clinical needs. Such an approach is wholly sufficient for many people living with a chronic condition; for those who do not have complex disease-related issues, the EPP is extremely beneficial. However, the EPP is not enough for people living with a complex chronic disease (CCD), such as HIV or hepatitis, which involves multiple morbidities and complicated treatment regimens and which requires the attention of multiple health care professionals.<sup>10</sup> As Sevick *et al.* write, patients with a CCD present the modern health care system with unique needs, disabilities and functional limitations.<sup>10</sup> They require bespoke self-management programmes that address their condition-specific needs, as well as those needs shared by others with less demanding long-term illnesses.

For this reason, in addition to the CDSMP, Stanford University has created a number of disease-specific courses, one of which is the PSMP, a self-management programme designed specifically for people living with HIV. This is a seven-week course delivered once a week for two and a half hours, each session facilitated by two trained tutors, who themselves are living with HIV; the PSMP is therefore similar in structure, content and delivery to the CDSMP but, importantly, is one week longer than the CDSMP and is specifically designed to address the needs of people living with HIV. Its aim is to give participants greater confidence in coping with HIV. It enables them to gain the skills and techniques to improve their quality of life and maintain their physical, psychological and mental health and wellbeing. As well as covering the material in the EPP, it focuses on issues such as:

- deciding whether to take antiretroviral therapy;
- medication adherence;
- dealing with possible side-effects of treatment;
- sex, intimacy and disclosure;
- laboratory tests, such as CD4 cell counts and viral load estimations.

Like the CDSMP, one of the most important aspects of the PSMP is that it is a peer-led initiative facilitated by trained lay tutors. Many of the tutors have completed the PSMP themselves and, for participants, knowing that one, or both, of their facilitators are themselves living with HIV is an extremely important inspirational aspect of the programme. Not only does it provide them with ‘positive role models’ but it also shows them that the techniques they are learning can work. Many participants say that they leave the PSMP with a real belief that there is life beyond HIV.

The PSMP does not conflict with existing programmes or treatment. It is designed to enhance regular treatment and HIV-specific education.<sup>11</sup>

### Living Well and the PSMP in the UK

Living Well is an NHS-funded organization that offers a wide range of health-related services designed to increase confidence, improve decision-making abilities and enhance self-esteem. In 2002, Living Well became the first organization to attain the licence to deliver the PSMP in the UK and it immediately began to roll out the programme across London. Today, Living Well remains the largest provider of the PSMP in the UK, working within the NHS and giving support and consultation to other organizations across the country that wish to deliver the PSMP.

Up to April 2008, Living Well had delivered the PSMP to more than 400 participants and trained over 50 new PSMP facilitators. Living Well also works in partnership with local, national and international voluntary and not-for-profit organizations to deliver the programme outside the UK. For example, in 2005/06, Living Well worked with the Institute of Cultural Affairs International to deliver a pilot of the PSMP in Kenya and Uganda, funded by the Elton John AIDS Foundation. More recently, Living Well has piloted the PSMP in China and there are plans to introduce the programme to other countries in Europe and Africa.

All Living Well’s PSMPs are independently evaluated by Thames Valley University (London). For the evaluation, participants complete pre- and post-programme questionnaires designed to examine participants’ knowledge, plans for the future, medication adherence and overall perceptions of the programme.

Results from a recent three-year evaluation (2005–08) of Living Well’s PSMP involving 218 participants found that:

- 98% of participants felt the PSMP had been worthwhile;
- 94% said it met their expectations and that they would recommend it to others;
- 92% thought the PSMP had helped them feel more in control;
- 83% said it had helped them to make informed choices about HIV medication;
- 93% thought that the PSMP had helped them to manage their condition more effectively;

- 93% reported that it had helped them to take more responsibility for their health;
- 90% said the PSMP had helped them to develop and improve their social networks and had enabled them to provide informed support for others;
- 92% felt that it had helped them to explore personal options and make action plans;
- 87% thought it had helped them to build personal strategies to support sexual health, general health and wellbeing;
- 89% said the PSMP had helped them to gain greater confidence in coping with HIV.

When asked what changes they would now make as a result of what they had learned on the PSMP, participants tended to focus on their intentions to improve their general health through better diet and exercise; and to use techniques such as action planning, distraction and problem solving to help improve the overall quality of their lives. Participants stated that they wanted to be more assertive and more confident and to work harder to break the 'vicious cycle'. A representative sample of quotes from PSMP participants is given below:

**I feel more confident and more organized. I know have a strategy for dealing with my problems.**

**I feel better-equipped to solve my own problems and ask others for help when I need it. I don't feel helpless any more.**

**I have become a much more positive person. I look forward to helping others and being more positive in every area of my life.**

**From now on I will take a more pro-active approach to life. I'll get out of isolation and make more use of action planning for day-to-day problems.**

**I would like this programme to be available to everyone.**

## The future of Living Well's PSMP

Living Well's PSMP continues to achieve its goal of making life better for people living with HIV. The PSMP supports self-care by providing participants with the tools they need to move beyond their HIV status, enabling them to manage their condition more effectively. It boosts their confidence, widens their horizons and encourages them to build supportive social

networks. Along with the EPP, the success of the PSMP is a positive manifestation of the UK government's commitment to patient self-management and self-care.

In 2008, Living Well completed a year-long project to update the PSMP and make it more appropriate to a UK audience. Living Well now offers to interested organizations the new PSMP along with a range of other services aimed at improving the lives of people living with HIV. To find out more about Living Well's PSMP or any of its other services, please visit the website [www.livingwelluk.com](http://www.livingwelluk.com), or email [admin@livingwelluk.com](mailto:admin@livingwelluk.com), or call +44 (0)20 8746 2274.

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## HIV transmission rates in the United States

The US Centers for Disease Control and Prevention (CDC) has estimated that approximately 1.1 million persons are living with HIV in the United States. This number is expected to continue to increase over time, as antiretroviral treatments prolong the lives of

those who are infected and more people become infected with HIV than die from the disease each year. As the prevalence of HIV increases, so does the opportunity for HIV transmission to others. Although the annual HIV incidence has remained stable in the United States in recent years, these estimates do not provide a full picture of the effect that HIV prevention efforts are having across

the country. To understand the impact of prevention efforts on the US HIV epidemic, Johns Hopkins researcher Dr David Holtgrave conducted an analysis designed to measure the annual rate of HIV transmission in the United States. Holtgrave worked with CDC researchers to apply the latest annual data on new HIV infections in the United States to this analysis. The resulting measure, the

transmission rate, represents the annual number of new HIV infections transmitted per 100 persons living with HIV. Put simply, the transmission rate compares the annual number of new infections to the number of persons living with HIV, and indicates the likelihood that an HIV-infected individual will transmit HIV to others. In this way, it provides a better means to assess the effects of public health efforts to promote changes in risk behaviour as well as the preventive effects of HIV diagnosis and treatment.

The researchers found that the HIV transmission rate has declined dramatically since the early days of the epidemic. In 1980, for example, when the disease was still undetected, the transmission rate was 92%, meaning there were 92 transmissions per 100 persons living with HIV in that year. After the identification of AIDS, and later HIV, and the implementation of HIV testing and other prevention efforts, transmission rates began to decline. Since the peak level of new infections in the mid-1980s, just before the introduction of HIV testing, the transmission rate has declined by approximately 89%, from 44 transmissions per 100 persons living with HIV in 1984 to just 5 transmissions per 100 persons living with HIV in 2006. Over the last decade, as prevention efforts have been expanded and improved treatments for HIV have become available, the transmission rate has declined by 33%, from an estimated 8 transmissions per 100 persons living with HIV in 1997 to 5 in 2006. Five transmissions per 100 persons living with HIV in 2006 means that 95% of persons living with HIV did not transmit the infection that year.

These data underscore the importance of reaching all infected individuals with HIV testing and prevention services. Previous research has shown that the majority of people who know they are infected take steps to prevent transmission to their partners. CDC currently estimates that approximately one in five persons living with HIV in the US is

unaware of their infection and may be unknowingly transmitting the virus to others.

CDC will continue to work on a number of fronts to reduce the impact of HIV across the nation by:

- expanding access to prevention programmes;
- increasing HIV testing and knowledge of HIV status
- improving surveillance;
- exploring new prevention approaches.

Communities and public health partners are working to tailor prevention efforts to meet local needs, mobilize communities and expand the reach of HIV prevention.

The findings also indicate that people living with HIV are taking steps to protect themselves and their partners from infection. They add to several recent signs of success in HIV prevention: the stable incidence in recent years; dramatic declines in mother-to-child HIV transmission; and declines in new infections among injection drug users and heterosexuals. Despite these successes, however, the number of people living with HIV in the US continues to grow. HIV continues to take a severe toll on multiple communities in the US, with gay and bisexual men of all races, African Americans and Latinos bearing the heaviest burden.

Source: CDC report, December 2008

## Record numbers living with HIV in the UK

An estimated 77,400 people were living with HIV in the UK in 2007, with more than a quarter (28%) unaware of their infection, according to figures released in November 2008 by the Health Protection Agency (HPA). This compares with the estimated 73,000 reported to be living with the infection in 2006. In 2007 there were 7734 new diagnoses of HIV – a similarly high figure to previous years (7334 in 2006).

The estimated number of people infected through heterosexual

contact within the UK has increased, from 540 new diagnoses in 2003 to 960 in 2007, and has doubled as a proportion of all heterosexual diagnoses during this period, from 11% (540/4800) in 2003 to 23% (960/4260) in 2007. Diagnoses among gay men continue to increase, with 3160 men (41% of all new diagnoses) testing positive in 2007.

Almost a third (31%) of individuals are being diagnosed with HIV late – at a point after which therapy should have begun (i.e. when the CD4 cell count had fallen to less than 200 per mm<sup>3</sup>) – which means that they are missing out on the benefits associated with early diagnosis, including prolonged life expectancy. Dr Valerie Delpech, Head of HIV surveillance at the HPA's Centre for Infections, said:

**Diagnosing HIV infections earlier will reduce transmission of this infection as those unaware of their positive status pose a greater risk to future sexual partners. Late diagnosis also has a major impact on disease and life expectancy and it is vital that people are diagnosed early. It is very worrying that so many people remain unaware of their HIV status. Wider HIV testing in high-prevalence areas of the UK is urgently needed to reduce the number of undiagnosed infections.**

New national testing guidelines recommend wider HIV testing in those areas of the country where the prevalence of HIV infection is greatest and state that health professionals should offer HIV testing to all men and women aged 15–59 who are either registering in general practice or being admitted for medical care. These areas include London, parts of the south coast, Manchester and Blackpool, where prevalence has historically been high. Dr Delpech said:

**Access to testing must be made easier. We need to improve availability of HIV testing in a number of health care settings, including general practice, to improve diagnosis of this infection. Without this we will not see the reduction in transmission that we need to see.**

Two reports were published in last November by the HPA, both of which are available online: *HIV*

in the United Kingdom: 2008 Report ([www.hpa.org.uk/hivuk2008](http://www.hpa.org.uk/hivuk2008)); and *Sexually Transmitted Infections and Men Who Have Sex with Men in the UK: 2008 Report* ([www.hpa.org.uk/hivmsm2008](http://www.hpa.org.uk/hivmsm2008)).

Source: HPA press release, 25 November 2008

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## United Nations report on children and AIDS

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A new report from four UN agencies entitled *Children and AIDS: Third Stocktaking Report, 2008* is advocating increased HIV testing for newborns as young as six weeks. It was coordinated to be released on 1 December – World AIDS Day. The jointly prepared report focuses on four core components: the prevention of mother-to-child transmission of HIV (PMTCT); paediatric treatment; preventing infection among adolescents; and protection and care for children affected by HIV/AIDS.

Early and accurate diagnosis coupled with proper treatment can significantly improve the survival prospects of newborns who have been exposed to HIV. The stocktaking report cites the study 'Children with HIV Early Antiretroviral Therapy', which demonstrated a 76% reduction in mortality when treatment was initiated within the first 12 weeks of life. Yet, in 2007 globally, less than 10% of infants born to mothers living with HIV were tested before they were two months old.

Counselling and support are critical for new mothers living with HIV. The report recommends increased access to HIV testing for mothers and pregnant women. In 2007, only 18% of pregnant women in low- and middle-income countries were given an HIV test.

The section of the report on prevention in young people and adolescents notes that school-based programmes can be a crucial avenue for reaching them with gender-sensitive information and life skills. For example, an 'HIV

Alert School' model has been adopted in Ghana as a national strategy for school-based HIV prevention. Parent–teacher associations and school management committees at these schools discuss HIV and AIDS as part of their regular meetings. On average, about 30% of males and 19% of females between the ages of 15 and 24 years in developing countries have comprehensive and correct knowledge about HIV and how to avoid transmission.

The last section of the report advocates expanded protection and care for the approximately 15 million children globally who have lost either one or both of their parents through AIDS.

*Children and AIDS: Third Stocktaking Report 2008* was jointly prepared by UNICEF, the World Health Organization, UNAIDS and the United Nations Population Fund. It is available online at [www.unicef.org/publications/index\\_46585.html](http://www.unicef.org/publications/index_46585.html).

Source: UNAIDS press release, 1 December 2008

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## Tackling hepatitis C across the UK

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The UK All Party Parliamentary Hepatology Group (APPHG) produced a report entitled *Divided Nations: Tackling the Hepatitis C Challenge Across UK* in January 2009. It shows that there are vastly inconsistent approaches in how hepatitis C is being tackled across the UK. The report shows Scotland is leading England and Wales in its response to the public health challenge, with the most effective multidisciplinary approach in the form of a two-phase Action Plan. Wales is yet to publish its Action Plan, originally due in 2006. The report calls for its immediate publication by the Welsh Assembly Government, as well as a new liver strategy in England to encompass hepatitis C.

Scotland is investing £43 million to address the totality of hepatitis C prevention, care, support and

treatment. This is a stark contrast to England, where there has been only £7 million of dedicated funding, confined to disease-awareness activities. Although England was first to launch an Action Plan, in 2004, it has had a limited effect on tackling the disease:

- almost two-thirds of primary care trusts are failing to implement the Action Plan effectively;
- only 3% of diagnosed patients are receiving treatment each year;
- awareness among general practitioners remains low;
- inadequate infrastructure is a major constraint.

Lack of targets, benchmarks, timetables or detailed actions has also made it difficult to measure implementation and success of the plan. The Department of Health is, however, launching a new disease-awareness campaign in England.

The Scottish approach tackles hepatitis C by embracing all relevant services: schools, prisons, the voluntary sector, local authorities (including social and mental health services) and National Health Service boards. The plan allows boards to take different measures, according to their local need and epidemiology, to target hepatitis C in their local populations. In addition, national guidelines for improvements to all needle/syringe exchanges and a pilot programme of an in-prison needle/syringe exchange have been developed.

Source: Hepatitis C Trust press release, 14 January 2009

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## Transmission of hepatitis B and C in US health care settings

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In the last decade, more than 60,000 patients in the United States were asked to get tested for hepatitis B virus (HBV) and hepatitis C virus (HCV) because health care personnel in settings outside hospitals failed to follow basic infection control practices, according

to a new study by the Centers for Disease Control and Prevention (CDC). A first full review of all the CDC investigations over the past 10 years of outbreaks of viral hepatitis associated with health care appeared in the 6 January 2009 issue of *Annals of Internal Medicine*.

Dr John Ward, Director of CDC's Division of Viral Hepatitis, said:

**This report is a wake-up call. Thousands of patients are needlessly exposed to viral hepatitis and other preventable diseases in the very places where they should feel protected. No patient should go to their doctor for health care only to leave with a life-threatening disease.**

In the United States, transmission of HBV and HCV while receiving health care has been considered uncommon. However, the review revealed a total of 33 identified outbreaks outside of hospitals in 15 states during the past decade: 12 in outpatient clinics, 6 in haemodialysis centres and 15 in long-term care facilities, resulting in 450 people acquiring HBV or HCV infection.

Patients were exposed because health care personnel failed to follow basic infection control procedures and aseptic technique in injection safety. Reuse of syringes and blood-contamination of medications, equipment and devices were identified as common factors in these outbreaks.

Dr Denise Cardo, Director of CDC's Division of Healthcare Quality Promotion, said:

**More and more patients in the United States receive their health care in outpatient settings. To protect patients, infection control training, professional oversight, licensing, innovative engineering controls and public awareness are needed in these health care settings.**

The report shows the need for ongoing professional education for health care providers, as well as consistent state oversight in detecting and preventing the transmission of blood-borne pathogens in health care settings. CDC and its partners are working to address this important patient safety problem

through a number of efforts, including:

- improving viral hepatitis surveillance, case investigation and outbreak response;
- strengthening the capacity of state and local viral hepatitis prevention programmes;
- augmenting the CDC's National Healthcare Safety Network, the national surveillance system for tracking health-care-associated infections, to collect information on outpatient settings;
- working with the Hepatitis Outbreaks' National Organization for Reform (HONOReform), a patient advocacy foundation, to create patient and provider education materials;
- continued improvement of injection safety practices through educational outreach efforts with professional nursing and anaesthesiology organizations;
- working with partners in the dialysis, diabetes and long-term care communities to promote safe care practices;
- working with regulators and professional societies to strengthen licensure and accreditation processes, with emphasis on safe injection practices;
- exploring ways to improve curricula in nursing and medical schools related to safe health care practices.

Source: CDC press release, 6 January 2009

## Deaths from hepatitis C: a legacy of our past behaviour

Many hepatitis C infections in the UK stem from recreational injecting drug use that began in the 1960s, according to a new report from the Health Protection Agency (HPA), *Hepatitis C in the UK*, an annual report for 2008 (available online at [www.hpa.org.uk/hepC2008](http://www.hpa.org.uk/hepC2008)). It is thought that around 250,000 people in the UK have ever been infected with hepatitis C, with only a quarter

of these expected to have cleared the infection. It is estimated that around a half of people living with hepatitis C have not been tested for the infection and are unaware they have contracted it. Without treatment, these individuals will be living with the virus and are at risk of developing serious liver disease.

Dr Helen Harris, a hepatitis C expert from the HPA, said:

**Hepatitis C is a disease many people associate with current drug use, but we should not forget people who could have been infected many years ago and are unaware of their infection. For example, people may have been infected by sharing needles once or twice when they were younger, and are now living stable, everyday lives.**

In England, the HPA has estimated that the number of people becoming infected increased dramatically after 1960, reaching almost 15,000 new infections in 1988. This increase is now being reflected in deaths from liver disease more than two decades later.

People who feel that they may have unknowingly put themselves at risk are being urged to come forward and get tested. The number of laboratory-confirmed diagnoses of hepatitis C infection in England reported to the HPA in 2007 was 7540, a 12% increase on the previous year. This increase suggests that more people are coming forward to be tested. Much of the increase is thought to be due to increased awareness about hepatitis C among both health care workers and the public.

The main risks in the UK are injecting drug use and the sharing of contaminated needles or equipment, and receiving a blood transfusion before screening began in 1991. People born and raised in high-prevalence countries (many countries in Africa, Latin America and central and south-eastern Asia) could have also been infected through other forms of blood exposure, such as unsterile medical equipment.

Source: HPA press release, 10 December 2008