

Swindon's Joint Strategic Needs Assessment

Bulletin 3: Hepatitis B and C



Key Points

- The JSNA provides evidence to help us understand the health care related needs of those with Hepatitis B and C in Swindon.
- Hepatitis is a term used to describe inflammation of the liver. There are a number of causes of hepatitis; this needs assessment focusses on the blood borne viruses Hepatitis B & C.
- Whilst some hepatitis infections will pass without causing permanent liver damage others can persist and cause liver disease which can be fatal.
- Treatments are available for those diagnosed with Hepatitis B and C; however the number of people treated is low both nationally and locally.
- Understanding how many people in Swindon are affected by Hepatitis B and C is difficult. Many infections are undiagnosed and there are limitations associated with the way laboratory data are collected. It is estimated that 627 people in Swindon have an ongoing Hepatitis B infection, and between 519 and 836 people are living with Hepatitis C.
- There are some very good services to support people affected by Hepatitis B and C but testing and diagnosis needs to expand, and access to treatment improve, in order to prevent further infections and unnecessary liver disease and deaths.
- Specialist Hepatitis C care is provided by the John Radcliffe Hospital in Oxford. Patients find travel there difficult.
- The JSNA makes eleven recommendations – these are set out on pages 7 & 8.

What is Joint Strategic Needs Assessment?

Joint Strategic Needs Assessment (JSNA) helps us to understand:

- what we know about the current health and wellbeing needs of local people;
- how their needs are being met;
- what we think their future needs are likely to be; and
- how their needs can be best met.

The JSNA process involves many different partners and is overseen by Swindon's Health and Wellbeing Board.

Understanding Swindon's changing population, the factors that affect health and wellbeing, the town's assets and the implications for future services are vital in setting priorities and planning future services.

The Hepatitis B & C JSNA

This needs assessment explores the health care related needs of those infected with Hepatitis B and C in Swindon. It focusses on the main stages of the care pathway for each of the viruses.

- Testing
- Diagnosis and referral
- Initial assessment
- Specialist management and treatment

Areas of prevention relating to healthcare provision including vaccination and screening are also discussed.

Hepatitis is a term used to describe inflammation of the liver. There are a number of causes of liver disease; this needs assessment focusses on the blood borne viruses Hepatitis B & C. Whilst some hepatitis infections will pass without causing permanent damage to the liver others can persist for many years and cause liver disease, which can be fatal.

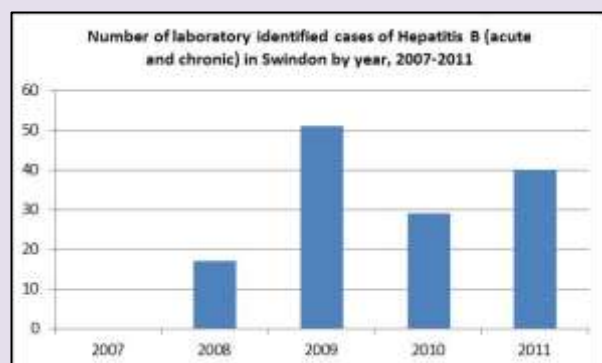
Liver disease is a government priority. It is associated with substantial morbidity and mortality and costs to the NHS related to hospital inpatient admissions and liver transplants and these costs are expected to increase. Yet liver disease is largely preventable.

Improving prevention, screening and access to treatment for those with chronic Hepatitis C infection have been the focus of work in Swindon for a number of years. With the abolition of Primary Care Trusts on 31st March 2013 and the move of Public Health to Local Authorities and much of local NHS commissioning to GP led Clinical Commissioning Groups the need to draw together the learning from previous work in to one document, and to clarify the need for service improvements was identified. Because of the parallels between Hepatitis B and C in terms of risk groups and pathways in to treatment it was felt that the opportunity should be taken to include both infections in this needs assessment.

The findings show that whilst only a small proportion of the Swindon population are affected by Hepatitis B and Hepatitis C numbers are expected to grow. Whilst there is strong commitment amongst professionals to support those affected by the viruses, and some excellent services available, testing and diagnosis needs to expand and access to treatment improve in order to prevent further infections and unnecessary liver disease and deaths.

There are strong arguments for investing in prevention and treatment for hepatitis.

- To prevent further infections
- To reduce under-75 mortality from liver disease
- To reduce costs to the NHS
- To reduce health inequalities



Source: Health Protection Agency - extracted from CoSurv on 23/11/2012

How many people in Swindon have Hepatitis B and C?

Understanding how many people in Swindon are affected by Hepatitis B and C is difficult. Both infections are largely symptom free which means that many individuals remain undiagnosed and only a small proportion of come into contact with treatment services. There are also limitations associated with the way in which laboratory data are collected.

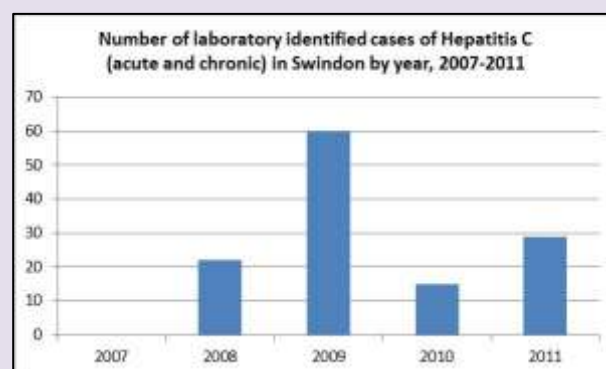
This needs assessment has collected data from a range of sources to build a picture of the likely numbers of people affected in the area. The following estimates based on national prevalence data can be made:

National Prevalence Estimate	Expected cases in Swindon
Chronic Hepatitis B infection - 0.3%	627
Chronic Hepatitis C infection - 0.4%	836

The Health Protection Agency has produced a template to help local areas estimate the prevalence of Hepatitis C in their population more accurately. It takes account of the estimated number of injecting drug users (IDU) in the population and also ethnic mix.

Population Group	Estimated cases in Swindon
Infected current IDU (15-64y)	208
Infected ex-IDU (15-64y)	232
Infected non-IDUs (16-59y)	47
Infected Asian/Asian-British (16-59+y)	28
Infected Asian/Asian-British (60+y)	5
TOTAL	519

This estimate is lower than the crude estimate of 836 shown above; the true value is likely to lie somewhere between the two.



Source: Health Protection Agency - extracted from CoSurv on 23/11/2012

Risk factors and high risk groups

Hepatitis B and C are blood borne viruses, which mean that they can be transmitted through contact with infected blood or other body fluids.

Whilst there are differences between the infections, both are known to affect vulnerable population groups who tend to have less contact with health services than the general population.

Hepatitis C transmission is mainly through contaminated blood. Injecting drug use is the most important risk factor for infection in the UK.

Hepatitis B can also be transmitted as a result of blood-to-blood contact. Transmission also occurs through sexual intercourse and from mother to child during pregnancy or at birth. In the UK, the majority (95%) of chronic Hepatitis B infections are diagnosed in migrant populations, and were acquired at birth, most often outside the UK.

Hepatitis B High Risk Groups

- People born or brought up in Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands.
- Babies born to mothers infected with Hepatitis B.
- People who have ever injected drugs.
- Men who have sex with men.

Hepatitis C High Risk Groups

- People who have ever injected drugs.
- People who received a blood transfusion before 1991 or blood products before 1986, when screening of blood donors for hepatitis C infection, or heat treatment for inactivation of viruses were introduced.
- People born or brought up in a Africa, Asia, the Caribbean, Central and South America, Eastern and Southern Europe, the Middle East and the Pacific islands.
- Babies born to mothers infected with Hepatitis C.
- Prisoners, including young offenders.

Prevention of Hepatitis B and C

Actions required to prevent Hepatitis B and C infection include:

- increasing awareness of infection
- promoting safer sex and condom use,
- reducing injecting drug use,
- safer injecting services
- universal precautions in health care settings
- Hepatitis B vaccination
- increasing testing and diagnosis
- getting diagnosed individuals into treatment and care.

What do local people and organisations think?

As well as collecting data, part of this needs assessment included discussions with representatives from key services in the care pathway, and a focus group with Hepatitis C service users to find out about their views of local services. Quotes from these meetings are presented with the findings below to give a flavour of what local people and organisations think.

What services do people use?

In Swindon services for people at risk of or infected with Hepatitis B and C are delivered via a range of services including local GP practices, Great Western Hospitals Trust, the John Radcliffe Hospital in Oxford, drug and alcohol services and other voluntary organisations.

There is currently no formal pathway for Hepatitis B or C in Swindon that covers the whole patient journey from testing through to specialist management and treatment, although specific pathways for antenatal screening and vaccination of babies born to Hepatitis B positive mothers are in place.

A key aim of this needs assessment was to map the patient pathways for Hepatitis B & C in Swindon. The figure below shows the services offering testing and referral routes in to specialist treatment identified.



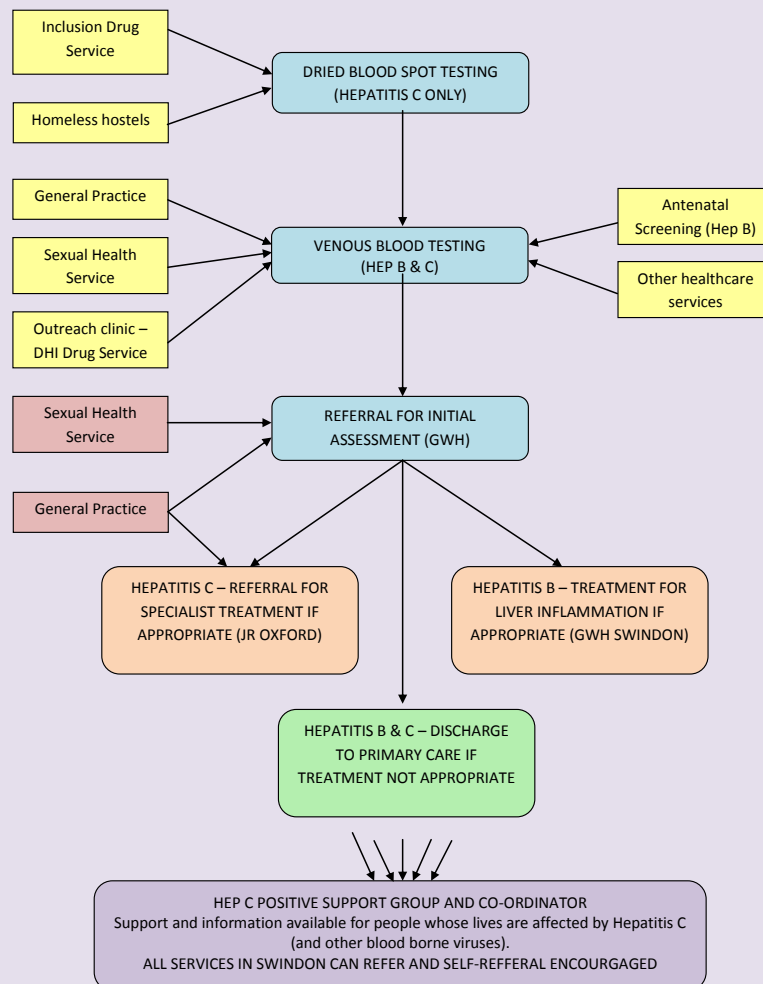


Diagram showing routes in to testing and treatment for Hepatitis B & C in Swindon
 (From 1st April 2013 services provided by the drug services Inclusion and DHI have moved to the new service provider CRI).

• Vaccination

Hepatitis B is a vaccine preventable disease. There is no universal Hepatitis B vaccination programme in the UK; immunisation is recommended for 'at risk' groups

There is no central data collection point for Hepatitis B vaccination and it is therefore difficult to get an overall picture of the number of vaccines given annually in Swindon, or the proportion of those in 'at risk groups' who have been vaccinated.

Injecting Drug Users have been a particular target group for Hepatitis B vaccination. A review of vaccination data available through the National Drug Treatment Monitoring System suggests that coverage could be improved. The introduction of the new service provider, CRI provides an opportunity to review current vaccination provision and ensure that it is easily accessible to all those accessing drug services in Swindon.

• Testing

One of the main challenges with Hepatitis B and C is the substantial number of people who are unaware of their infection. In order to identify those who are infected and would benefit from treatment a diagnosis is required so that a referral to specialist care can be made.

Testing is recommended for those at increased risk of Hepatitis B or C infection in primary care, in prisons and youth offender institutions, in immigration removal centres, in drugs services in genitourinary medicine and sexual health clinics.

Testing for Hepatitis B and C is available in Swindon in a range of settings, including:

- Primary Care including Shared Care Services for drug users
- Genitourinary Medicine (GUM)/Sexual Health Services
- Drug and Alcohol Services
- Antenatal screening

No systematic review of the level of testing in Primary Care in Swindon was undertaken as part of this needs assessment, however discussions with stakeholders suggested that there is little targeted screening of high risk groups carried out and low awareness amongst GPs of Hepatitis B and C.

Testing for Hepatitis C in drug services in Swindon is done through both venous and dried blood spot testing. Discussions with stakeholders and service users highlighted a number of challenges to the current system of testing, and improvements which could be made. These were related to the lack of consistency in the way in which testing is offered and data sharing between services.

Overall, no issues were identified in this health needs assessment about access to testing through Sexual Health Services. However, concerns were raised about the lack of information sharing, particularly between Sexual Health and Drug Services.

"We could do a lot more – more testing and vaccination. We have the staff, we just need the resources."

(Service Provider)

"We need better information sharing; we don't want to waste resources repeat testing, but we don't want to miss people."

(Service Provider)

There are opportunities to extend testing for Hepatitis B and C in Primary Care and drug services in Swindon and to ensure that all those in 'high risk' groups are routinely offered testing according to NICE Guidelines.

• **Diagnosis and initial assessment**

Diagnosis of Hepatitis B and C, and assessment of appropriateness for onward referral requires a number of tests and investigations. For most patients in Swindon these tests will be done in Primary Care, although investigations for those identified in Sexual Health Services remain within that service. Those identified as Hepatitis C positive through dried blood spot testing must be referred to their GP to arrange confirmatory blood testing.

Following diagnosis patients are referred to the Gastroenterology Department at the Great Western Hospital for an initial assessment. All GP Practices in Swindon are able to refer their

patients to this service. The Sexual Health Service refers patients directly.

Waiting times for a first appointment were 2-3 months at the time stakeholder interviews were held (January 2013). Service users consulted as part of this needs assessment reported a lack of support following diagnosis, and the need for better co-ordination of care between services, particularly when waiting for their first assessment.

"There needs to be some sort of level of counselling for when people are told they've got Hep C. There's a sort of stigmatism that Hep C is lethal, there's no treatment"
(Service User, Hepatitis C)

"You're in that half-way stage. You've got this disease. You don't know much about it. You can go on the internet and that frightens you to death reading about liver damage and all those kind of things."
(Service User, Hepatitis C)

• **Treatment**

Treatments are available for those diagnosed with Hepatitis B or C. Management consists of infection control and lifestyle advice and support, assessment and monitoring of liver function and consideration for antiviral treatment.

The average cost of treating someone identified with Hepatitis B is £3,474 in the first year and £9,085 for someone with Hepatitis C. There are also likely to be some ongoing costs for treatment, particularly for Hepatitis B as treatment can be required for several years. These costs compare well to the cost of care for liver disease; annual cost for a person with decompensated cirrhosis is £12,432 and of someone with hepatocellular carcinoma £11,0784 whilst a liver transplant costs more than £50,000.

Limited data was available about the numbers of patients being treated for their infection in Swindon. Nationally the number of patients being treated is low; it is estimated that only 26% of those with chronic Hepatitis B have had their infection diagnosed and of these 5% receive antiviral treatment each year, whilst approximately 3% of those chronically infected with Hepatitis C are currently treated each year.

Year	Number of Hepatitis C Patients Treated in John Radcliffe Hospital, Oxford (2007-2011)
2007/2008	7
2008/2009	10
2009/2010	10
2010/2011	13

In Swindon management of Hepatitis B is overseen by the Gastroenterology Department at the Great Western Hospital. Specialist Hepatitis C care is provided by the John Radcliffe Hospital in Oxford. Patients with Hepatitis C report receiving excellent care in Oxford, and the number treated has increased over recent years. However travel is difficult.

*"Having to travel to Oxford when you're feeling really rubbish – it's a real grind."
(Service User, Hepatitis C)*

• Social Support

Not all those diagnosed will seek treatment for their infection immediately. The Hepatitis C Positive support provides peer support to those directly or indirectly affected by the Hepatitis C and other blood borne viruses. It meets weekly and is facilitated by former service users.

*"It was only when the Hep C Positive group...it was the first time I'd ever met anyone with Hep C. I wish I'd had that when I first found out. I had 3 years counting my life down. I just kept thinking "what's the point?" – I'm going to be dead in 10 years.
(Service User, Hepatitis C)*

*"One of the reasons why the support is so successful is because we tell everybody that the treatment is hard...but at the end of it it's beneficial."
(Service User, Hepatitis C)*

In February 2012 the Swindon treatment system employed a Blood Borne Virus Co-ordinator to run a project with the principal aim of 'following up' service users who had agreed to a dried blood spot test for Hepatitis C. The role of the co-ordinator is to work with those people who have not acted upon their test results through counselling and/or involvement in the Hepatitis C Positive support group, and to improve links with health care and drug service providers to ensure that drug service users are provided every opportunity to gain supportive advice and interventions commensurate with blood borne virus status.

The role of the Co-ordinator, working in partnership with Hepatitis C Positive group has provided a highly valued source of support to many people living with Hepatitis C in Swindon and has been successful at identifying people in Swindon needing support and helping them to come to terms with their diagnosis and move in to treatment. It also supports some people affected by Hepatitis B and HIV.

What Does the Future Look Like?

There is little published data on future population projections for Hepatitis B in England. The number of new acute cases appears to be reducing; this is likely to be due to interventions to prevent transmission in drug users such as needle exchanges; antenatal screening; and improved vaccine uptake amongst high risk groups. However, since most cases of chronic Hepatitis B are diagnosed in immigrant populations prevalence is dependent on global immunisation policy as well as national efforts and there is evidence that the prevalence of chronic Hepatitis B in the UK is increasing as a result of migration.

Researchers predict that, under current treatment patterns, the overall prevalence of Hepatitis C infection will increase from 0.4% in 2010 to 0.61% in 2035. This equates to an increase in the number of persons in the UK living with Hepatitis C infection from around 265,000 in 2010 to 370,000 in 2035. A crude calculation based on the estimated Swindon population size in 2021 suggests that there would be 1198 people in Swindon living with Hepatitis C infection in 2021. This does not take account of the number of intravenous drug users and ethnic mix that the HPA template does.

Alternative Scenarios

When considering what the future might look like and alternative scenarios evidence suggests that the most important intervention would be to improve uptake of testing in those at increased risk of Hepatitis B and C. This is considered to be cost effective by the National Institute of Health and Clinical Excellence (NICE) and would have wide ranging benefits.

Detecting people with either disease will allow them to be treated if appropriate. This will subsequently lead to a reduction in the severity of adverse events associated with untreated disease. It should also increase the number of people who are vaccinated against Hepatitis B. Successful completion of treatment and

subsequent clearance of the virus will also reduce the risk of onward transmission.

Whilst increasing the number of people being tested is important it is also essential that there is adequate capacity within accessible secondary care and specialist treatment services to manage the increased demand this creates.

In Swindon this creates both opportunities and challenges. A key priority for the Swindon's Clinical Commissioning Group is to commission local services in order to ensure people have a positive experience of their care. Although patients report receiving excellent care in the John Radcliffe Hospital, in this context there is clearly a need for change to the current requirement for those with Hepatitis C to travel to Oxford for their treatment.

There are models of innovative care both regionally and nationally which could be explored in Swindon to improve access to care for both Hepatitis B and C. These include nurse led in-reach from a hospital based service; a community based Blood Borne Virus or Hepatitis Nurse; care provided by a GP with a Special Interest; or non-clinical community based support to complement hospital based treatment.

Recommendations

This needs assessment provides a chance to reflect on the needs of people with Hepatitis B and C in Swindon and the potential future demand for services, identify good practice and make further progress in improving services. A set of recommendations based on the evidence collected for this needs assessment, national best practice and NICE Public Health and Clinical Guidelines and are set out below.

It should be noted that a whole system approach to implementing these recommendations is required, with collaboration between commissioners and service providers at all stages of the care pathway.

1. Local service providers and community and voluntary groups including the Blood Borne Virus Co-ordinator should work together with support from Swindon Borough Council Public Health leads to develop and deliver evidence based campaigns, materials and resources to raise awareness about Hepatitis B and C among the general population and those at increased risk of infection. This should build on existing

nationally produced materials wherever possible and include up-to-date information on:

- The main routes of infection and transmission
- Local services providing testing and Hepatitis B vaccination
- The potential for infection to be asymptomatic
- The benefits of early testing and treatment
- Overcoming social and cultural barriers and improve access to testing and treatment

2. Swindon Borough Council Public Health leads should work with local commissioners and service providers to develop and deliver education programmes to improve the knowledge and skills of healthcare professionals and others providing services for people at increased risk of Hepatitis B or C infection. This should build on existing nationally produced materials wherever possible and include up-to-date information on:

- Epidemiology of Hepatitis B and C – local prevalence, at risk groups
- Testing and diagnosis
- Treatment
- National guidance on testing and delivery of care
- Skills to overcome social and cultural barriers and improve access to testing and treatment

3. Commissioners in the Local Authority, Clinical Commissioning Group and NHS Commissioning Board should ensure testing for Hepatitis B and C (venous and/or dried blood spot as appropriate) and Hepatitis B vaccination is available in-line with NICE Guidance in:

- Primary Care
- Drug and Alcohol Services
- Sexual Health Services

4. Swindon Borough Council Drug and Alcohol Treatment Commissioners should work with the new Swindon drug service provider, CRI, to ensure that all service users entering drug treatment are routinely offered Hepatitis B and C testing and Hepatitis B vaccination at their initial assessment, and that annual testing for Hepatitis C is offered to people who test negative but remain at risk of infection. Commissioners should routinely audit data collected.

5. Services providing testing should ensure that all those who undertake testing are trained and competent to provide appropriate pre- and post-test discussions and that testing is accompanied by appropriate information resources and support while waiting for test results and following diagnosis.
6. A named commissioning lead for viral hepatitis should be identified in the Swindon Clinical Commissioning Group, NHS Commissioning Board Local Area Team and Swindon Borough Council who should agree ways to work together to ensure effective commissioning of a fully integrated care pathway for those who test positive for Hepatitis B or C infection from the point of diagnosis. This should take account of the patient's psychosocial and support needs as well as treatment for their infection and include mechanisms for following up patients who defer treatment.
7. Swindon Borough Council Public Health leads should work with Commissioners and Service Providers to develop clear data recording and sharing protocols which support those receiving positive results for Hepatitis B or C to access support and move along the treatment care pathway as appropriate, and which enable the number and source of referrals for Hepatitis B and C; appointment attendance; treatment and discharge or onward referral to specialist services to be monitored.
8. Swindon Clinical Commissioning Group Commissioners should audit services available for the management and treatment of Hepatitis B and C in Swindon and ensure compliance with NICE Guidelines when they are published.
9. Swindon Borough Council Public Health leads should work with Antenatal Screening Commissioners in the NHS England Local Area Team to undertake regular audit of the Hepatitis B vaccination programme for babies in Swindon and pathways for mothers identified as Hepatitis B positive, and take action if standards are not being met.
10. Findings of this needs assessment should be used by the Clinical Commissioning Group to consider redesign of current treatment pathways. This should include development of an options appraisal outlining models of care which would support and improve access to specialist Hepatitis B & C treatment services for patients in Swindon. Options might include:
 - a. A nurse led in-reach service from the John Radcliffe Hospital in Oxford for Hepatitis C treatment.
 - b. A nurse led service providing co-ordinated care and support hosted by the Great Western Hospital (Gastroenterology or Sexual Health Department).
 - c. A community based Blood Borne Virus or Hepatitis Nurse (possible hosting organisations suggested by stakeholders in this needs assessment include Carfax Medical Centre or CRI).
 - d. Development of the Blood Borne Virus Co-ordinator pilot and the Hepatitis C Positive group to provide non-clinical community based support for all those diagnosed with Hepatitis B and C.
 - e. Development of a GP with a Special Interest role in Swindon.
11. Swindon Borough Council Public Health and Drug and Alcohol Commissioners should work together to evaluate the role of the Blood Borne Virus Co-ordinator (and Hepatitis C Positive group) and secure ongoing funding for the projects.

Where to find more information

The full Hepatitis B & C JSNA provides much more information on the issues covered by this bulletin (including full references). It can be found on Swindon's JSNA website:

www.swindon.gov.uk/healthandwellbeing

The website includes a range of other documents about health and wellbeing in Swindon. If you have any queries (or would like to contribute to needs assessment activities in Swindon) please contact:

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This bulletin will be reviewed in June 2015.