

Protecting and improving the nation's health

Annual review of the epidemiology of Hepatitis C infection in Yorkshire and Humber

Field service Yorkshire and Humber

2017 data

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Executive summary

In the UK, it is estimated that approximately 113,000 people are chronically infected with hepatitis C (HCV), the majority of whom are from marginalised and under-served groups in society, such as people who inject drugs1¹.

In 2017 in Yorkshire and Humber 18.9 people per 100,000 were newly diagnosed with hepatitis C (1,020 people). This remains the highest rate of any region outside of London but on par with the rate for England.

Injecting drug use continues to be the most important risk factor for HCV infection, being cited as the risk in around 90% of all laboratory reports where risk factors have been disclosed.1 Population groups with the highest burden of hepatitis C infection in Yorkshire and Humber continue to be those aged 25 to 54 years of age.

Around twice as many males than females are diagnosed with hepatitis C in Yorkshire and Humber, possibly influenced by testing of targeted groups, however it is important to ensure that cases in older age groups and females are not being under-diagnosed as over the age of 25 more males than females are tested for hepatitis C. More males test positive (2.9% compared to 1.4% in 35 to 44 year olds). Ethnicity is a factor that is not well recorded with 41% of cases having no data on ethnicity.

Considerable local variation in numbers of new hepatitis C diagnoses by local authority areas continues to be observed across Yorkshire and Humber. The 2 local authority areas with the highest rates of new diagnoses in 2017 were Doncaster and Leeds, although Doncaster continues a year on year decrease in cases. Eight local authority areas across Yorkshire and Humber saw a decrease in number of cases in 2017 compared to 2016, including a notable reduction in Wakefield, with North East Lincolnshire, Rotherham and Bradford also showing sizable decreases.

Sharing of injecting equipment by people who use drugs has fallen, with only 15% of PWIDs reporting direct sharing and 34% reporting direct or indirect sharing. Just over eight out of 10 (84%) people who inject drugs report they are aware of hepatitis C. The number of first registrations for a liver transplant in Yorkshire and Humber due to hepatitis C has reduced to 30 in 2014 to 2017, down from 53 in 2010 to 2013.

¹ Hepatitis C in the England 2019. Public Health England. Available at: https://www.gov.uk/government/publications/hepatitis-c-in-the-uk

The national 'Hepatitis C in England: 2019 report' contains a series of specific public health recommendations in 4 key areas.

- 1. Making improvements and monitoring metrics.
- 2. Adequate harm reduction/prevention.
- 3. Increasing the numbers and proportion diagnosed.
- 4. Increasing the numbers accessing hepatitis C treatment.

We hope the data in this report will help support commissioners, providers, local authorities and other stakeholders to help drive the implementation of these recommendations in Yorkshire and Humber.

Introduction

Hepatitis C is caused by the blood borne hepatitis C virus. The early stage of infection is usually asymptomatic. Most people who are infected cannot clear hepatitis C naturally, and without successful treatment chronic infection can span several decades or be lifelong. Persistent infection can lead to end stage liver disease and liver cancer (hepatocellular carcinoma).

The following report includes hepatitis C data from a range of different sources. Given this, it is important to note that, while none of these data sources in isolation will provide a complete record of all hepatitis C infections, together they provide a representative overview of the burden of the disease and its epidemiology.

The section below highlights the caveats associated with specific data sources that must be considered when interpreting data in this report. A consequence of the multiplicity of data sources used in this report is the potential for disagreement between figures, which therefore need to be considered in the context of the datasets from which they are derived. The biggest challenge in reporting the epidemiology of hepatitis C is the incomplete nature of available intelligence due to the pool of undiagnosed infections. Additionally, there is the issue of providing anonymised testing to encourage more people to come forward and be tested or treated for hepatitis C. This offer of anonymity creates a potential for duplicate records within anonymised datasets.

Data sources and resources

The following resources have been used in compiling this report:

- Hepatitis C in the UK Public Health England Annual report, 2018²
- Hepatitis C Workbook_2017 an Microsoft Excel workbook produced by FES West Midlands

² Hepatitis C in England 2018 report. Public Health England, 2018. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/693917/HCV_in_England_201 8.pdf

The data sources below have been used within this report. Each source has been assigned a colour code to make it easier to identify the data source used for individual charts and tables.

SGSS (Second Generation Surveillance System) laboratory data from Yorkshire and Humber NHS laboratories Sentinel surveillance of hepatitis testing Unlinked anonymous monitoring survey of HIV and hepatitis in people who inject drugs

Office for National Statistics

Please note: 2017 HES data on hospital admissions for HCV-related ESLD and HCC is not included in this report due to an issue with classification of HCV codes by NHS Digital. As a result, unique identifiers that can link an individual to their hospital admission data were removed from some HCV-positive patients. The issue is temporary and has since been resolved, but prevented the de-duplication of multiple admissions for the same individual in 2017. Therefore, 2017 data suggested that there had been a drastic increase in the incidence of HCV-related ESLD and HCC which does not reflect a true increase in incidence.

NHS laboratory data

NHS laboratory data on hepatitis C should be interpreted with caution as there may be differential use of diagnostic methods between NHS laboratories and testing by non-NHS laboratories in different parts of the country. This may affect hepatitis C data available for inclusion in the NHS laboratory dataset.

This data includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C nucleic acid (RNA). Due to the variability in the quality of laboratory reports, and the inability of current serological assays to differentiate acute from persistent infections, it is not possible to estimate the actual proportion of cases with evidence of past infection or persistent infection.

Mothers with antibody against HCV usually pass this maternal antibody to their newborns. However most of these babies are not actually infected with HCV. The antibodies that may be detected in a newborn's blood are most often maternal antibodies that were passed to the baby before birth. A baby born to a mother with hepatitis C will probably have maternal antibodies to the virus for the first 12 to 18 months of life. Therefore the baby will test positive for antibodies to HCV irrespective of whether the baby is infected. For this reason tests in those aged under one are excluded from the data.

Tables and graphs in this report that use NHS data reported to the PHE surveillance system (SGSS) include all newly-diagnosed cases of acute and chronic (past and persistent infections of) hepatitis C.

Sentinel surveillance scheme

The sentinel surveillance of blood borne virus testing began in 2002, with the aim of supplementing routine surveillance data. Information on the testing carried out in participating centres is collected irrespective of test result and can therefore also be used as a basis for estimating prevalence among those tested. Limitations of the data include some duplication of individual patients (subject to availability of date of birth, Soundex and first initial) and exclusion of dried blood spot, oral fluid, reference testing, and testing from hospitals referring all samples which do not have the original location identified.

Individuals aged less than one year, in whom positive tests may reflect the presence of passively-acquired maternal antibody rather than true infection, are also excluded. There are 2 actively participating sentinel surveillance centres in Yorkshire and Humber, Leeds and Grimsby. Together they provide estimated population coverage of 20% to 39%. While the data is not comprehensive for the whole region, it provides a useful demographic and epidemiological profile of hepatitis C infection in Yorkshire and Humber.

The sentinel surveillance scheme uses the computer programme NamPehchan to complete missing ethnicity data. NamPehchan is a computerised classification system used to identify possible South Asian names and to assign likely religion and language.

Fingertips data

Fingertips is a set of interactive online health profiles that provides data in relation to a range of indicators across health and wellbeing themes, designed to support local authority joint strategic needs assessments and commissioning. The data also provides users with the ability to compare indicators with their neighbours. Indicators related to liver disease can be found here: https://fingertips.phe.org.uk/profile/liver-disease

Missing data

In September 2016, the laboratory at Leeds Teaching Hospitals NHS Trust suffered a serious information system failure which resulted in data being lost and unrecoverable for the time period September 2016 to March 2017. This has affected SGSS laboratory data and Sentinel Surveillance data, for both Leeds and Bradford (due to Leeds providing testing and reporting on behalf of Bradford).

Leeds also provided the majority of sentinel surveillance data for Yorkshire and Humber. Assessment of sentinel surveillance data over multiple time points requires continuous data submissions for the entire period and as a consequence of the data loss, Leeds data has been excluded where there are multiple time points. The impact of this loss is that Yorkshire and Humber sentinel surveillance data for individual time points has been dramatically reduced and to avoid spurious inferences due to the resulting small numbers sentinel surveillance trend data has been excluded from this report.

Epidemiology

NHS laboratory data

In 2017 in Yorkshire and Humber 18.9 people per 100,000 were newly diagnosed with hepatitis C. This remains the highest rate of any region outside of London but on par with the rate for England. This continues an overall downward trend since 2014 in the number and rate of new cases. The rate reported in 2016 was artificially low due to the loss of data experienced by the Leeds laboratory (Figure 2).

Figure 1. Rate of all newly-diagnosed cases of hepatitis C infection per 100,000 resident population by PHE centre of residence and England, 2017



Figure 2. Number and annual rate per 100,000 resident population of all newly-diagnosed cases of hepatitis C for Yorkshire and Humber, 2008 to 2017



NHS laboratory data show that there is considerable variation in the numbers and rates of new diagnoses of hepatitis C between local authority areas in Yorkshire and Humber (Table 1 and Figure 3). The 2 local authority areas with the highest rates of new diagnoses in 2017 were Doncaster and Leeds, although Doncaster continues a year-on-year decrease in cases. Eight local authority areas across Yorkshire and Humber saw a decrease in number of cases in 2017 compared to 2016. Figure 3 shows a notable reduction in the rates of Hepatitis C seen in Wakefield, with North East Lincolnshire, Rotherham and Bradford displaying sizable (though less statistically certain) decreases.

Although considerable increases have been observed in Hull and Sheffield compared to 2016, this is mainly due to reporting issues at the laboratories, where testing codes had changed, but were not updated within SGSS. This means data for 2016 and 2015 is likely to be under-reported in Hull and Sheffield. These have since been updated and data for 2017 is likely to reflect more accurate rates and numbers of cases for Sheffield. The 2017 data for Hull is likely to still be an under-estimate due the reporting issue recurring from May 2017. Backdated data from 2016 to 2017 for Sheffield and Hull will be included in future publications.

Upper Tier Local	Rate per 1 (95% c	00,000 popula confidence inte	Numbers			
Authonity	Rate	LCI	UCI	2016	2017	Change
Doncaster	32.7	26.34	39.37	117	100	Ŧ
Leeds	31.1	26.95	34.84	208	241	
Barnsley	29.1	22.42	36.34	57	70	
North East Lincolnshire	27.9	20	36.96	52	44	₹
Bradford	20.5	16.57	24.38	129	108	₹
Kingston upon Hull	19.8	14.57	25.72	15	51	
North Lincolnshire	19.5	13.26	27.06	28	33	
York	19.4	13.73	26.17	40	40	
Sheffield	17.5	14.08	21.05	43	100	
Rotherham	14.6	10.21	19.8	61	38	₹
Wakefield	13.4	9.63	17.67	78	45	₹
Calderdale	11.6	7.34	17.05	27	24	Ŧ
Kirklees	11.6	8.49	15.08	60	50	₹
North Yorkshire	9.1	6.77	11.7	56	55	₹
East Riding of Yorkshire	6.3	3.85	9.5	17	21	
Yorkshire and Humber	18.9	17.58	19.9	988	1020	
England	18.5	17.94	18.65	10962	10176	Ŧ

Table 1. Number and rate per 100,000 resident population of all newly-diagnosed cases of hepatitis C in Yorkshire and Humber by upper tier local authority and England, 2017. Data includes individuals with a positive test for hepatitis C antibody and/or detection of hepatitis C RNA.

Source: SGSS – NHS laboratory data

There does not appear to be a distinct urban/rural pattern to variation by local authority areas and the observed pattern is likely skewed by the distribution of prison populations or accessibility to testing services. It is also important to consider that this laboratory data includes hepatitis C antibody test results which may not reflect recent infections.





Figure 4 shows the rates per 100,000 population of newly-diagnosed hepatitis C across Yorkshire and Humber as reported in Table 1. Doncaster, Leeds, Barnsley and North East Lincolnshire have the highest rates. The predominantly rural areas of East Riding of Yorkshire and North Yorkshire have the lowest rates. North East Lincolnshire, Wakefield, Rotherham and Bradford all showed sizable reductions in rates of hepatitis C in 2017.

Figure 4. Rate per 100,000 resident population of all newly-diagnosed cases of hepatitis C by local authority, Yorkshire and Humber, 2017



In Humberside and North Yorkshire the number of individuals tested in 2017 was similar to the previous 2 years while the proportion testing positive has been steady at around 2% since 2013 (Figure 5).



Figure 5. Number of individuals tested and % testing positive for anti-HCV in sentinel laboratories, Humberside and North Yorkshire* ODN 2013-2017

*Data not available for South and West Yorkshire

Source: Sentinel surveillance data

Demographics

Age group and sex profile

The age distribution of hepatitis C positivity identified through the Sentinel Surveillance Scheme shows a consistent peak between 35 and 44 years of age across the country (Figure 6).

In Yorkshire and Humber, the majority of hepatitis C cases identified are aged 35 to 44 years (Figure 6) – representing 33% of all laboratory-confirmed cases. It is important to note however that those aged 45 and older may be accessing a different range of diagnostic services than younger cases and may not be represented here. The peak in the 35 to 44 age group is largely driven by males (Figure 7).







Figure 7. Number of cases and rate per 100,000 resident population of all newlydiagnosed cases of hepatitis C by age group, Yorkshire and Humber, 2017

Source: SGSS – NHS laboratory data

In keeping with national epidemiology, the overall burden of hepatitis C in Yorkshire and Humber is much higher among males than females, with a case ratio of approximately 2:1 (Figures 8 and 9). This male predominance may reflect the gender bias among some of the known risk associations for hepatitis C, such as injection drug use and having a custodial sentence, but this may be confounded by increased opportunities for testing possibly introducing a case ascertainment bias.

Figure 8. Age and sex distribution of all newly-diagnosed cases of hepatitis C in Yorkshire and Humber, 2017



Figure 9. Age and sex distribution of individuals testing positive for antibodies to hepatitis C virus in sentinel laboratories in Yorkshire and Humber, 2013 to 2017



Table 2 shows the numbers of individuals tested and those testing positive for Hepatitis C by age and sex. Under the age of 25 the numbers of male and females being tested is roughly equal. Over 25, the number of females being tested reduces compared to the number of males. While positivity rates are higher for males in all age groups, the positivity rate was still 1.2% to 1.5% in females aged 25-54.

Table 2. Number of individuals tested and those testing positive for antibody to hepatitis C virus by age group and sex reported through the sentinel surveillance scheme, Yorkshire and Humber, 2013 to 2017*

	Female			Male			Unknown			Total		
Age group (years)	Number tested	Number positive	% positive									
1-14	1313	9	0.7	1286	12	0.9	5	1	20.0	2604	22	0.8
15-24	9811	61	0.6	9640	68	0.7	59	0	0.0	19510	129	0.7
25-34	17244	206	1.2	19486	432	2.2	126	3	2.4	36856	641	1.7
35-44	13450	190	1.4	18660	542	2.9	175	3	1.7	32285	735	2.3
45-54	9401	138	1.5	13646	335	2.5	110	1	0.9	23157	474	2.0
55-64	7500	68	0.9	9967	139	1.4	32	0	0.0	17499	207	1.2
65+	9776	31	0.3	12068	54	0.4	13	1	7.7	21857	86	0.4
Unknown	218	3	1.4	171	3	1.8	4	0	0.0	393	6	1.5
Total	68713	706	1.0	84924	1585	1.9	524	9	1.7	154161	2300	1.5

*Data are de-duplicated subject to availability of date of birth, Soundex and first initial. All data are provisional.

Source: Sentinel surveillance data





Ethnicity profile

There were a total of 1,813 individuals tested for HCV, of which 1.98% were positive. Four in 10 (41%) were of an unknown ethnic group. Just over half (56%) were in the White ethnic group, 1.9% were Asian and 0.4% were Black. However, given the large proportion of people with unknown ethnicity these figures may not accurately reflect the ethnicity of the population tested.



Figure 11. Number of individuals tested and % positive for anti-HCV by ethnic group, sentinel laboratories, Yorkshire and Humber PHE centre, 2013 to 2017

Source: Sentinel surveillance data

Risk factors

Information on risk exposure and indications for testing is limited and absent for many cases of hepatitis C within sentinel surveillance data. Figures for 2013 to 2017 show that the indication for testing was not recorded in 50% of cases. Confirmatory tests and screening tests made up 23% of the positive results. Discounting cases where the reason for testing was screening or confirmatory tests, or the reason was unknown, injection of drugs remains the most frequently declared reason for testing for hepatitis C in Yorkshire and Humber (Figure 12).

Figure 12. Risk factor* and reason for testing of individuals testing positive for antibody to hepatitis C virus in sentinel laboratories in Yorkshire and Humber, 2013 to 2017



*Individuals where the reason for testing was unknown have been removed.

Source: Sentinel surveillance data

Sentinel surveillance data for 2013 to 2017 highlights the strong relationship between hepatitis C positivity and a reported history of injection of drugs (Table 4). Where injected drug use was reported, 17.5% of those individuals tested were positive for hepatitis C. The relatively high level of positivity among patients being investigated for elevated liver enzymes (1.7%) is to be expected, and contributes to 4.5% of the total (Table 4). There is no formal hepatitis C screening within the antenatal screening programme, however it is worth noting that antenatal specimens accounted for 3% of the total number of positive cases, with a 1.4% positivity rate.

No reason for testing was recorded for a high number of sentinel laboratory reports, accounting for 48% of all positive test reports (Table 4). It would clearly be beneficial to understand the reasons for testing of these samples to provide the most relevant recommendations for treatment and care pathways.

Table 4. Risk exposures and reasons for testing for individuals testing positive for antibodies to hepatitis C virus in sentinel laboratories in Yorkshire and Humber, 2013 to 2017

Risk exposure/reason for testing	Number tested	Number positive	% testing positive	% of all positive cases	% of all cases excluding confirmatory
Study participants	< 5	-	-	-	-
Travel or lived abroad	202	< 5	-	-	-
Fertility treatment					
screening	8212	7	0.1	0.3	0.3
Maternal/vertical exposure	176	9	5.1	0.4	0.4
Contact testing	253	10	4.0	0.4	0.5
Needlestick donor/recipient	2233	16	0.7	0.7	0.8
Other medical condition	3739	18	0.5	0.8	0.8
Renal patient	11832	18	0.2	0.8	0.8
Sexual exposure	1523	18	1.2	0.8	0.8
Symptoms (non-liver)	2153	32	1.5	1.4	1.5
Risk of infection	1129	37	3.3	1.6	1.7
Antenatal screening	4839	68	1.4	3.0	3.2
LFTs - abnormal result	6223	104	1.7	4.5	4.9
Liver disease symptoms	3339	123	3.7	5.3	5.8
Confirmatory test	3042	169	5.6	7.3	-
PWID	1218	213	17.5	9.3	10.0
Screening	26739	352	1.3	15.3	16.5
Unknown	77307	1104	1.4	48.0	51.8
Total	154161	2300	1.5	100	

PWID = people who inject drugs; LFT = liver function tests.

Source: Sentinel surveillance data

Drug dependency services and prison services are the most commonly identified source of positive specimens, although a larger number of tests are performed (but with lower numbers of cases detected) in primary care services (Figure 13).





† Other ward types includes cardiology, dermatology haematology, ultrasound, x-ray.

‡ This refers to infectious disease services, hepatology departments and gastroenterology departments.

^ These are hospital services which are currently being investigated to identify specific service type, and may include any of the secondary care services mentioned above.

§ These services are currently being investigated to identify specific service type, where possible.

Source: Sentinel surveillance data

Information drawn from the Unlinked Anonymous Monitoring Survey of HIV and Hepatitis in People Who Inject Drugs demonstrates that awareness of hepatitis C infection among this demographic has remained at a similar level since 2008, with around two-thirds (65%) of people aware of hepatitis C in 2017 (Figure 14). Uptake of HCV testing within this time period has increased steadily from 76% to 84%.





As sharing of injecting equipment and associated paraphernalia is the main route of transmission of infection among people who inject drugs, it is important to monitor levels of sharing within this population. In England in 2017, 18% of people currently injecting psychoactive drugs and participating in the UAM survey, reported direct sharing of needles and syringes.³ In Yorkshire and Humber, direct sharing of injecting equipment was reported by 15% of people who inject drugs (Figure 15). One in 3 people reported direct and indirect sharing of equipment (including the sharing of mixing containers or filters as well as needles and syringes). Both figures have reduced since 2016 but have not fallen below 2008 levels.





³ *Hepatitis C in the England 2019.* Public Health England. Available at: https://www.gov.uk/government/publications/hepatitis-c-in-the-uk

The prevalence of Hepatitis C in people who inject drugs when broken down by Operational Delivery Network (ODN) is shown in Figure 16. ODNs are the structures through which hepatitis C treatment in England is being delivered. The prevalence of Hepatitis C was 56.2% for South Yorkshire and Humberside and North Yorkshire, while in West Yorkshire the prevalence was 57.4%.





Source: Unlinked anonymous monitoring survey of HIV and hepatitis in people who inject drugs

The uptake of testing for Hepatitis C in people who inject drugs in each ODN is shown in Figure 17.

Around 9 in 10 people who inject drugs took up testing for Hepatitis C across Yorkshire and Humber. The exact figures were 87% in South Yorkshire and Humberside and North Yorkshire, and 86% in West Yorkshire.



Figure 17. Percent HCV test uptake in people who inject drugs by ODN, 2016 to 2017

Source: Unlinked anonymous monitoring survey of HIV and hepatitis in people who inject drugs

Morbidity and mortality

Over the past decade, morbidity and mortality from HCV have been on the increase in England as people who acquired their infections decades previously progress to advanced liver disease.

There were 30 first registrations for a liver transplant in Yorkshire and Humber where post-hepatitis C cirrhosis was given as a reason⁴ for transplant being needed between 2014 and 2017, down from 53 in the 2010 to 2013 period. There were 35 liver transplants in the same period to individuals with hepatitis C, accounting for 12% of all liver transplants.⁵

Figure 18. Number of first registrations⁶ for a liver transplant in England where post-hepatitis C cirrhosis was given as either the primary, secondary or tertiary indication for transplant, residents of Yorkshire and Humber PHE centre, 2010 to 2013 and 2014 to 2017



Figure 19. Number of first liver transplants⁵ for patients with post-hepatitis C cirrhosis as either primary, secondary or tertiary indication for transplant at registration or patients who were HCV positive at registration or transplant, residents of Yorkshire and Humber PHE centre, 2010 to 2013 and 2014 to 2017



⁴ Where it was the primary, secondary or tertiary indication for transplant.

⁵ Patients with post-hepatitis C cirrhosis as either primary, secondary or tertiary indication for transplant at registration or patients who were HCV positive at registration or transplant, recorded between 2014-2017, ⁶ These figures are based on registry data as at 5 August 2018 and include both elective and super urgent registrations.

With a 16% fall in deaths between 2015 and 2017 in England, the WHO target to reduce HCV-related mortality by 10% by 2020 will have been met 3 years early. This suggests that increased treatment provision (a 127% increase in 2017/18 compared to pre-2015 levels), together with new direct-acting antiviral (DAA) drugs is having an impact. The creation of operational delivery networks (ODNs) in 2016 aimed to deliver DAA drugs to significantly reduce the number of individuals progressing to serious HCV-related ESLD/hepatocellular carcinoma (HCC) and reduce the premature mortality that results.

Figures 20 and 21 show the number and rate of deaths from Hepatitis C related end stage liver disease (ESLD) or hepatocellular carcinoma (HCC) across England by PHE Centre.

Figure 20. Number of deaths from end stage liver disease (ESLD) or hepatocellular carcinoma (HCC) with HCV mentioned on their death certificate by PHE Centre 2008 to 2017



Data source: Office for National Statistics

Figure 21. Death rates (per 100,000 population) from end stage liver disease (ESLD) or hepatocellular carcinoma (HCC) with HCV mentioned on their death certificate by PHE Centre 2008 to 2017



* Defined by codes or text entries for ascites, bleeding oesophageal varices, hepato-renal syndrome, hepatic encephalopathy or hepatic failure.

** Based on 2008 to 2017 mid-year estimate population data

Data source: Office for National Statistics

About the Field Epidemiology Service

The Field Service (FS) is a part of Public Health England's National Infection Service (NIS) and provides local support to Public Health England and partner organisations through the application of epidemiological methods to inform public health action. FS does this in 2 main ways, firstly by providing a flexible expert resource, available, as and when needed, to undertake epidemiological investigations for key health protection work and secondly through the expert analysis, interpretation and dissemination of surveillance information to local PHE, health partners, service providers and commissioners of services. Within the FS network, excellence and innovation is encouraged, we foster academic collaborations and take active part and lead in research, development and training.

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