

# New Hepatitis C Treatments and HIV/HCV Co-infection — results of a survey of ODNs for 2016/17



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## 1. Introduction

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Hepatitis C co-infection is a significantly prevalent co-morbidity for people living with HIV in the UK. When NAT last looked at the issue as part of our report into HIV and injecting drug use,<sup>i</sup> we found that whilst a relatively small percentage of people who inject drugs have HIV, of that number a very high proportion are also HCV positive (83% in one 2010 study, for example). Amongst men who have sex with men (MSM) living with HIV about 9% were also HCV positive. Given how many more MSM there are living with HIV than there are people who inject drugs, the majority of co-infected patients are MSM.

A paper has recently been published which looks at the prevalence of HIV amongst people with hepatitis C in England between 2008 and 2014. 5% of people with a current HCV infection (PCR test) during this period had been diagnosed with HIV either before or in the 6 months following their HCV test. The majority of those co-infected were amongst MSM.<sup>ii</sup>

The route of transmission for HCV and HIV amongst people who inject drugs is mainly the sharing of injecting equipment. Recent attention to 'chemsex' behaviours has identified injecting ('slamming') also taking places among MSM. There may also be other routes for HCV transmission linked to sexual behaviours. There has historically been a high rate of re-infection with hepatitis C amongst MSM living with HIV who succeed in clearing hepatitis C through interferon-based treatment.

HIV/HCV co-infection worsens outcomes for the management of both conditions and complicates treatment and care. Whilst HIV remains a life-long incurable condition, there has for many years been interferon-based treatment for hepatitis C which does result in a cure (Sustained Virological Response or SVR) for many who undergo the treatment. However, this treatment has serious side-effects which are very difficult to tolerate and which results in many not completing the treatment or not being willing to begin treatment in the first place.

The prospects for hepatitis C treatment have more recently been transformed by the introduction of a new class of treatment called DAAs (Direct-acting antivirals). These new drugs are far more tolerable, with relatively few side effects, have a much higher rate of SVR achievement, and the course of treatment is significantly shorter than for interferon-based regimens. DAAs offer the prospect of the elimination of hepatitis C, if the high numbers currently undiagnosed are tested, brought into care and provided with treatment promptly.

DAAs are currently under patent and costly. NHS England decided to commission DAAs via 22 Operational Delivery Networks (ODNs) across England which would have a run-rate of DAA provision over specific time periods, and which they were expected not to exceed nor (significantly) under-perform against. It is up to each ODN to determine how to prioritise patients for DAA treatment. The run-rate also incentivises case finding and outreach to ensure there are patients available for treatment so that the run-rate is met.

NAT were interested to know how people living with HIV co-infected with hepatitis C were accessing the new DAA treatment under the ODN system, and what their outcomes were like. We drafted a questionnaire along with the Hepatitis C Trust to gather information on DAA treatment across ODNs in 2016/17, with a particular focus on those co-infected with HIV.

## 2. Methods

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The survey was sent to all ODN clinical leads on 25 May 2017, with a request for responses by 23 June. The response to the survey was very poor, despite repeated requests and reminders. A number of ODNs asked us to resubmit the survey as an FOI request—which we did to them in September 2017, following that up with an FOI request to the remaining ODNs who had not responded in November 2017. It still took considerable chasing to secure the 19 ODN responses finally received (the final response only arrived in June 2018!)—and we note that the responses vary in the fullness of the answers provided. Only three ODNs did not submit anything—Greater Manchester and Eastern Cheshire (who cited cost of gathering the information and responding), Surrey Hepatitis Services, and Bristol & Severn.

The substantial time it took to secure responses from ODNs has had an impact on NAT's capacity to analyse the data. Nevertheless, we have now looked at the survey responses and believe the results are of interest even if relating to 2016/17. It should be noted that whilst some questions were specific quantitative questions relating to 2016/17, other questions were of a qualitative nature or not time specific (for example the request for a copy of the ODN's engagement plan). In that responses came in over nearly a 12-month period, responses to these more qualitative questions will be affected by when the response was provided, and thus the stage in the development of the ODN and their changing perspective on their local epidemic and response.

A number of ODNs told us they had difficulty answering the questions comprehensively given their resources and capacity. As we shall go on to see, many ODNs were in any event, after extended delays in response, still unable to answer many questions. We do not believe the questions in the survey were complicated—on the contrary we consider them to be central to the ODNs activities and purpose.

**It is concerning that most ODNs were not able to respond in an acceptable timescale to questions about their activity over the previous year. This undermines accountability. ODNs should improve their preparedness to respond to reasonable enquiries relating to their policies, outputs and outcomes. This will enhance public trust and engagement with their vital work.**

## 3. Diagnosed prevalence, co-infection prevalence, and incidence of acute infection diagnosis

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The survey began with questions to each ODN asking 'How many people are known to be living with chronic HCV in your ODN area (i.e. overall HCV diagnosed prevalence) and how many of them are thought to be co-infected with HIV?'. Only four ODNs were able to answer this question straightforwardly and without caveats. These responses were 4,000 of whom 53 are co-infected; 1,174 of whom 20 are co-infected; 810 of whom 13 are co-infected; and 581 of whom 63 are co-infected. Thus the co-infection prevalence, as a percentage of the overall number diagnosed with hepatitis C, is fairly consistent across the first three ODNs of 1.3%, 1.7% and 1.6%, respectively – but in the last ODN cited, Sussex, there is a co-infection rate of 10.8%, which may relate to the significant HIV positive population of gay and bisexual men in the Brighton area.

One ODN gave us a figure for numbers with diagnosed hepatitis C (234) but did not have data on the registry on numbers co-infected. Two gave us the number—co-infected (997—a London ODN; and 10) but nothing for the overall number living with diagnosed hepatitis C.

Five ODNs, on the other hand, were unable to provide any data for overall diagnosed prevalence and the proportion co-infected.

Seven ODNs provided estimates, or extrapolations from data in specific clinics, or only figures of those in treatment or on the waiting list. For example, one ODN gave the 'guesstimate' of 3,000 with diagnosed hepatitis C of whom 30 are co-infected 'as true figures not known'. Another ODN gave the figure of 1,300 for one hospital trust and four co-infected, stating that this was about one half of the total population covered by the ODN. One ODN said they have 1,623 in treatment or on the treatment waiting list of whom 53 are co-infected, and another gave us only the numbers on the waiting list (376, of whom 181 co-infected). One ODN gave the data just for one hospital (1,609 of whom 73 co-infected).

**There is striking and significant variation across ODNs in their ability to provide data on the numbers living with diagnosed hepatitis C in their area, and the numbers who are diagnosed with HIV co-infection. This is essential information for case finding and treatment provision. Work is urgently needed to improve ODN data collection and recording to ensure it is consistent and comprehensive.**

**Co-infection rates amongst those diagnosed vary by region. There appear to be especially high rates in some major cities with significant populations of gay and bisexual men.**

The survey also asked how many people in the ODN area had been diagnosed with acute infection in 2016/17. Six ODNs gave low numbers (four ODNs stated there had been six, one said five and one said three). One London ODN stated there had been 46 diagnoses of acute infection in 2016/17. Two ODNs gave figures which seem too out of line with other responses to be credible ('upwards of 431' and 244), which suggests the question has been misunderstood.

### 4. Treatment in 2016/17

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The survey asked in 2016/17 how many mono-infected and co-infected people had been treated with DAAs in the ODN area. This would include people who had not at the time of responding to the survey completed treatment, even if they had begun the therapy. There was better data in response to this question—of the 19 responding ODNs 17 were able to provide data. In total 9,782 mono-infected people went on DAA treatment in 2016/17 and 1,037 co-infected people (a total of 10,819). It should be noted, however, that the two responding ODNs which could not include clear information on numbers treated were Cheshire and Merseyside, and North Central London. Bearing in mind also that one of the three non-responding ODNs to the survey was Greater Manchester and Eastern Cheshire, we can assume that the actual numbers treated in 2016/17 were significantly higher when numbers from the five missing ODNs are taken into account.

It is difficult from survey responses to get a sense of what proportion of people known in 2016/17 to be diagnosed with hepatitis C were able to commence DAA treatment. This is mainly because of the poor data provided on the numbers living with diagnosed hepatitis C in the ODN area. In very few instances did data seem reliable enough to make the comparison. In one ODN the number of mono-infected patients treated amounted to 87% of those diagnosed; equivalent percentages in three other ODNs with data were 33%, 35% and 47%.

### 5. Treatment completion in 2016/17 - achieving SVR

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The survey asked about treatment completion, including how many people receiving DAA treatment in 2016/17 had achieved SVR at 12 weeks from treatment completion (sustained virologic response, in effect a cure, and the goal of hepatitis C treatment). Of those where SVR status was reported, the vast majority achieved SVR, which is very welcome news and confirms the tolerability and effectiveness of these new drugs. Seventeen ODNs were able to provide numbers of patients who had achieved SVR and numbers who had failed treatment for mono-infected patients. The percentage of those mono-infected with hepatitis C who failed to achieve SVR, as a percentage of all patients where an outcome from treatment was reported, varied from 0.6% to 12.3%; the mean of percentage failure values was 4.5%; the median was 4.3%.

There was also data provided by 16 ODNs on treatment failure amongst people co-infected with HIV and hepatitis C. Given the low numbers of people co-infected, percentage values for treatment failure can be misleading. In terms of absolute numbers, of the 16 ODNs who could report, five reported that no co-infected

patients failed treatment, four reported that one did, four reported that two did; two reported that 3 did; and one reported that four did.

Summing responses from those 17 ODNs reporting SVR rates for mono-infected patients, 5,952 people achieved SVR, with 220 failing therapy, equivalent to 3.6% failing therapy. Summing responses from those 16 ODNs reporting SVR rates for co-infected patients, 803 people achieved SVR, with 22 failing therapy, equivalent to 2.7% failing therapy. **There is no significant difference between SVR rates for mono-infected and co-infected patients. SVR rates for patients who complete treatment and are tested for SVR at 12 weeks are encouragingly high.**

A few ODNs provided further useful information around treatment failure. In some instances SVR was not achieved because the patient had died. One ODN reported that of the fourteen patients treated who did not achieve SVR, two had died; another that out of 17 such patients three had died; one that of 26 such patients three had died. Another ODN had data only on co-infected patients treated (121) of whom nine had died, four of them being cirrhotic. **The deaths amongst those treated are a reminder of how vulnerable these patient populations are to early and preventable death, and the urgent need to roll out hepatitis C treatment effectively and promptly to save life.**

Alarming, one ODN having stated that 18 patients had failed therapy, then added that 120 mono-infected patients treated had either been lost to follow up or died and four co-infected patients had been lost to follow up — this out of a total of 704 mono-infected treated and 35 co-infected treated. This ODN is clearly not performing well in terms of retaining people in care and urgent action is required to improve performance. Another ODN cited 35 lost to follow up amongst the 420 who had 'completed' treatment. Some ODNs also mentioned that of those who had completed treatment, the SVR status of some was unknown because they had not (or not yet) attended for their SVR 12 week test.

Other ODNs did not give numbers but stated, for example, that '17 failed due to relapses, non-response to treatment, breakthroughs, DNAs, deceased and re-infections'. A couple of other ODNs gave precise breakdowns with similar causes identified—in one case out of 14 not achieving SVR, '1 non-responder, 1 breakthrough, 7 relapsers, 1 re-infection pre-SVR 12, 2 discontinued treatment early, 2 died'. And the other out of 17 such patients, '3 deceased, 3 discontinued because of side-effects, 3 lost to follow up, 1 non-responder, 5 relapsed, 2 transferred outside ODN and results unavailable, 1 (co-infected) allergy'.

## 6. Re-infection

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We asked over 2016/17 how many HIV positive patients had been diagnosed with re-infection of hepatitis C, and of those who had been thus diagnosed, how many had previously been successfully treated with DAAs. Only three ODNs reported any instances of re-infection—one cited three cases of whom one had previously been treated with DAAs. Two others cited <5 (this was to avoid possible identification of individuals), in one ODN none had previously been treated with DAAs and in the other <5 had.

One ODN said that re-infection was 'not automatically recorded' and another said they were 'unaware' of any re-infections.

We also asked about the ODN's policy on providing DAA treatment to people who have been re-infected with hepatitis C. The vast majority said that re-treatment was only possible if the individual has previously been successfully treated with an interferon-based therapy. Re-treatment of those who had been previously treated with DAAs was not possible. This was in line with explicit NHS England policy. A few cited the recently agreed NHS England policy on retreatment<sup>iii</sup>—but this applies to those who have previously failed DAA treatment, not to those who had achieved SVR.

One ODN said they had only been able to re-treat such cases on compassionate grounds with help from drug companies. One ODN referred to NHS England policy but then stated 'patients failing or re-infected post DAAs

are currently offered if they have CP-B/C cirrhosis or hepatic de-compensation’ —NHS England policy is in fact to re-treat in these circumstances those who failed treatment but not those re-infected after successful SVR. One ODN said they currently prioritised untreated patients and added, ‘We consider each case on an individual basis and we have re-treated some cases over the last 10 years—given the impetus to treat PWID this may become an increasing problem but if we are to impact on prevalence then re-treatment may become more common’.

It is encouraging to see hardly any instances of someone getting re-infected with hepatitis C after successful DAA treatment. We note two caveats. One is some uncertainty as to whether re-infection is systematically and consistently recorded and reported to ODNs. The second is that this does not capture those who may have been re-infected but have not yet been diagnosed (one respondent told us that a significant number of patients did not attend for testing as requested 12 weeks after SVR had been achieved).

Current NHS England policy is not to offer re-treatment for those re-infected with hepatitis C after successful DAA treatment. This policy appears to be adhered to by almost all, if not all, ODNs. Some respondents did suggest this policy would need to be looked at again as case finding became more challenging and as NHS England aimed to eliminate hepatitis C. We agree. **NHS England should allow people re-infected with hepatitis C, who had previously been successfully treated with DAAs, to be re-treated. To refuse such re-treatment smacks of punishment. Concerns about ongoing risk of re-infection need to be addressed by effective support services. Elimination of hepatitis C in England will not be possible without changing the policy on re-treatment.**

**Re-infection needs to be consistently recorded in healthcare records and reported to ODNs.**

## 7. Prioritisation

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We asked ODNs how they prioritised patients for treatment, given they work to a capped run rate of patients per month.

All ODNs stated that they prioritised according to liver failure, severe liver disease and by fibrosis score.

Other factors for prioritisation often cited were recipients of transplants, co-morbidities, wishing to conceive/pregnancy, time on waiting list, iatrogenic infection, extra-hepatic manifestations, optimal timing for treatment (including treatment windows such as short-term prison custody), infection risk to others, mental health and psychosocial issues.

With regard to co-infection with HIV, responses varied as to whether and the extent to which it resulted in prioritisation for treatment. Ten ODNs cited it as one factor to be considered in prioritisation (with drug-drug interaction being cited in one response as a key issue). Three ODNs said that they neither prioritised nor deprioritised people who are co-infected, with one of these stating they audited their patient cohort to ensure there was an appropriate proportion of co-infected patients being treated. Two ODNs referred to HIV status and lifestyle when considering prioritisation—it is unclear whether ‘lifestyle’ could be a reason not to prioritise for treatment.

There was not only variation in the factors cited in prioritisation but also in the process itself. Several ODNs said they did not have a scoring system in prioritising—it was instead a process of clinical judgement taking various factors into account. One ODN did not even have an ODN-wide system but left each clinic to determine their own priorities. Two ODNs did have a scoring card, and in one case shared it with their response. That scoring card awarded points based on various factors—for example, F4 fibrosis got 20 points, a short-term prison custody got 10, co-infection with HIV got 4. This underlines the point that ODNs simply stating co-infection is prioritised gives little information on its relative importance compared with other factors.

Six ODNs said that prioritisation was or had become an academic issue since they had treated all patients within the run rate and indeed were case finding for new patients. More generally, there was the sense that significant problems for ODNs, as a result of their run rates, in treating all patients wanting to access DAAs were now limited to only a few areas.



The survey also asked how often the prioritisation process was reviewed by the ODN and how any such reviews were communicated to patients. Most said they reviewed their prioritisation either quarterly or every six months. There did not seem for most ODNs to be a process whereby patients could hear of this ODN-level consideration of their prioritisation process – many ODNs interpreted the question to be about how the patient's individual prioritisation had been determined.

**Co-infection should be a factor in prioritisation for all ODNs based on the greater clinical complexity and worse prognosis of this patient group. We note that for most ODNs prioritisation of patients appears to be becoming less of an issue.**

**Deprioritisation of patients based on 'lifestyle' would be a concern.**

**Where prioritisation is taking place and some patients are being told they have to wait before accessing DAA treatment, it is important to explain clearly and transparently the prioritisation process to patients. It is as important to ensure patient input into regular ODN consideration of prioritisation policy. There does not seem much evidence that such consultation on prioritisation policy is occurring.**

### 8. Expectations of future issues in the run rate

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ODNs were asked whether they envisaged in 2017/18 any issues with meeting the treatment run rates (and if yes, what measures they were putting in place to meet their run rate). Eleven of the 16 ODNs who responded to this question said that they did not envisage any difficulty in reaching their run rate for 2017/18. Two ODNs said they would have issues meeting the run rate. Three ODNs said there might possibly be issues and outlined, as did others, the actions they are taking to find cases and link them into treatment.

Interventions to ensure the required number of patients would enter DAA treatment (and 'to ensure continuous patient flow') included:

- more community-based testing and treatment
- dry blood spot testing in at risk communities
- opt-out BBV testing in A&E
- 'case-finding projects'
- outreach clinics in substance misuse services
- contract with virology to inform ODN of any HCV positive result
- case find with laboratories those diagnosed HCV positive but not referred to hepatology services

**Most ODNs are confident they will identify enough patients needing DAA treatment to meet their run rate in 2017/18. Survey responses cited many encouraging examples of case finding and outreach.**

### 9. Further care pathways for co-infected patients

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The survey asked what further care pathways were promoted to co-infected patients, and how such pathways might be improved. The question was asked in the context of historically high rates of re-infection with hepatitis C amongst co-infected patients who had achieved SVR. Care pathways can not only support diagnosis, and access to and retention in treatment, but also provide support to avoid risk of future hepatitis C transmission.

Most ODNs in their responses mentioned good links with and referral pathways to drugs services, sexual health clinics and mental health services. One ODN refreshingly added that whilst their referral pathways were 'good in principle ... testing rates and referral and retention of patients in the hepatitis C clinic need to be improved'. It is important to test pathways against actual outcomes, especially in the context highlighted above of some challenges to patients finishing therapy or appearing for their SVR 12-week assessment.

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Of course, many also emphasised the strong links and shared care pathways with HIV clinics and wider HIV services including peer support and the third sector. Three ODNs mentioned joint HIV/Hepatitis C clinics for co-infected patients.

A couple of London ODNs mentioned support around chemsex needs, and one mentioned dedicated psychological support for risk behaviour modification in advance of commencing DAA treatment. It was encouraging to see one ODN refer to dedicated social workers to help with access to mental health, housing, finances etc. Health advisors in another ODN were the key workers to support onward referral to other necessary services.

**There was an encouraging awareness amongst ODNs on the need for outreach, referral and shared pathways for co-infected patients into other services. It is important to test the effectiveness of such pathways against patient outcomes. Disappointingly, very few ODNs explicitly mentioned either chemsex or social needs such as housing, employment, finances and benefits. There is room for greater consensus and consistency across hepatitis C services in England in relation to wider care pathways.**

**10. Fibrosis scores and treatment**

The survey did ask about fibrosis scores of those treated. Only three ODNs provided us with this information.

Mono-infected patients					
ODN	F0	F1/F2 <sup>iv</sup>	F3	F4	Unknown
A	71	159	64	68	15
B <sup>v</sup>	242	85	49	88	-
C	45	66	13	8	-

Co-infected patients					
ODN	F0	F1/F2	F3	F4	Unknown
A	1	8	2	3	0
B	22	2	0	4	-
C	0	2	1	0	-

One ODN attached their ODN annual report which did not distinguish between mono- and co-infected patients but did say that over a seven-month period 111 patients with an F4 score were treated and 64 with scores F0-3. Additionally, one ODN provided us with a table of significant co-morbidities in cirrhotic and non-cirrhotic patients, whilst explaining that they did not have the detailed data available to answer the question on fibrosis scores. Relatively small numbers also had HIV or renal failure but there were high rates of contributing alcohol problems. Overall 200 patients were cirrhotic and 128 patients were not.

The sample of course is a very small one but **it is striking that even in this first year of DAA treatment a large number of people with low cirrhosis scores (i.e. less seriously ill) were treated.**

**11. Engagement plans**

We asked for a copy of the ODNs’ engagement plans—such plans are a requirement under CQUIN Governance payment Q1. Six ODNs neither provided a copy of the plan nor any information on their plan’s content. One strangely replied that the engagement plan could not be released since it was commercially confidential. A considerable amount of information was received from the other ODNs on engagement either in train or planned. Amongst the many actions cited some of the most commonly cited and most interesting ones included:

- ODN-wide educational events
- Workforce training/development e.g. of GPs, voluntary sector staff
- Media campaigns, social media, patient posters and leaflet
- Improved referral pathways
- Use of clinical nurse specialists for example in drugs and alcohol services
- Outreach into prisons, drug and alcohol treatment services and sexual health services
- Patients in peer/pathfinder roles, advising on outreach
- A mobile clinic pilot
- Dry-spot testing in pharmacies
- Educating at-risk communities including South Asian communities, people who use drugs, homeless people
- Clinical psychological support to those at risk of non-adherence
- Hepatitis C screening in key healthcare settings.

**There was a wealth of ideas and proposals in ODN engagement plans in 2016/17. It will be important to learn what in practice has been implemented, and how successfully, both in terms of outputs and in terms of impact/outcomes. It would be good to identify those interventions which appear to have most impact in case finding people living with hepatitis C and engaging those people in treatment and care.**

## 12. Patient experience

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We asked ODNs what process they undertook to assess patient experience. Such assessment is expected by NHS England which linked a CQUIN payment to patient experience assessments being undertaken (CQUIN Governance Payment Quarter 3). We also asked for them to share any results received and analysed.

Three ODNs gave a nil response. Two ODNs said they were still developing such a survey. Two ODNs referred to in one instance a small patient participation group which they hoped to expand further and in the other to a patient representative being invited to speak about their experiences at the quarterly ODN meeting—both of these approaches sound useful but cannot substitute for a more representative survey of the relevant patient population.

Four ODNs simply told us that they had such a patient experience (or patient satisfaction) survey and two further ODNs said additionally that it was as yet too early to analyse the results. We received six responses which not only confirmed they were surveying patient experience but also included information on the patient feedback/responses. Overall in the results reported there were high rates of patient satisfaction with the services provided. The surveys did however allow issues of delays in service access or treatment commencement to be raised in one ODN, and in another a serious problem in the quality of homecare services was brought to light which was then looked into with pharmacy colleagues. Challenges also came to light in the reach of the survey with one ODN noting that responses had been received from only three of their seven treatment centres and another saying 'feedback coverage is poor'.

In terms of good practice, a number of ODNs said that the results of patient surveys were regularly reviewed at ODN meetings and some also quite rightly referred to feeding back to patients themselves on the outcomes of such assessments. Some kept a survey open over a number of months; some sent a survey out 'on a regular basis'; one surveyed all patients over a week and repeated the process in six months' time; another asked patients to fill in a pro forma at their week 4 post-treatment visit, and another 12 weeks after treatment. We say the actual survey questions in four cases—the number of questions varied—five, 12, 14 and 25. There was no consistency in question wording but there were common themes of satisfaction with services, settings and appointments; questions on the clarity of information provided; and on how the patient was treated in terms of, for example, respect and dignity.

Patient representation on ODN boards and patient forums were also being developed by a number of ODNs.



There was significant variation in how far advanced ODNs were in assessing patient experience and satisfaction. It will be important for such assessments to continue, and for results to be regularly reviewed and acted on by ODNs as well as fed back to patients. It might be useful for ODNs to compare survey questions and have some core questions in common to support comparability across areas—patient representatives should be central to the development of such questionnaires.

### 13. Conclusions and Recommendations

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It is concerning that most ODNs were not able to respond in an acceptable timescale to questions about their activity over the previous year. This undermines accountability. ODNs should improve their preparedness to respond to reasonable enquiries relating to their policies, outputs and outcomes. This will enhance public trust and engagement with their vital work.

There is striking and significant variation across ODNs in their ability to provide data on the numbers living with diagnosed hepatitis C in their area, and the numbers who are diagnosed with HIV co-infection. This is essential information for case finding and treatment provision. Work is urgently needed to improve ODN data collection and recording to ensure it is consistent and comprehensive.

Co-infection rates amongst those diagnosed vary by region. There appear to be especially high rates in some major cities with significant populations of gay and bisexual men.

There is no significant difference between SVR rates for mono-infected and co-infected patients. SVR rates for patients who complete treatment and are tested for SVR at 12 weeks are encouragingly high.

The deaths amongst those treated are a reminder of how vulnerable these patient populations are to early and preventable death, and the urgent need to roll out hepatitis C treatment effectively and promptly to save life.

NHS England should allow people re-infected with hepatitis C, who had previously been successfully treated with DAAs, to be re-treated. To refuse such re-treatment smacks of punishment. Concerns about ongoing risk of re-infection need to be addressed by effective support services. Elimination of hepatitis C in England will not be possible without changing the policy on re-treatment.

Re-infection needs to be consistently recorded in healthcare records and reported to ODNs.

Co-infection should be a factor in prioritisation for all ODNs based on the greater clinical complexity and worse prognosis of this patient group. We note that for most ODNs prioritisation of patients appears to be becoming less of an issue.

Deprioritisation of patients based on 'lifestyle' would be a concern.

Where prioritisation is taking place and some patients are being told they have to wait before accessing DAA treatment, it is important to explain clearly and transparently the prioritisation process to patients. It is as important to ensure patient input into regular ODN consideration of prioritisation policy. There does not seem much evidence that such consultation on prioritisation policy is occurring.

Most ODNs are confident they will identify enough patients needing DAA treatment to meet their run rate in 2017/18. Survey responses cited many encouraging examples of case finding and outreach.

There was an encouraging awareness amongst ODNs on the need for outreach, referral and shared pathways for co-infected patients into other services. It is important to test the effectiveness of

such pathways against patient outcomes. Disappointingly, very few ODNs explicitly mentioned either chemsex or social needs such as housing, employment, finances and benefits. There is room for greater consensus and consistency across hepatitis C services in England in relation to wider care pathways.

It is striking that even in this first year of DAA treatment a large number of people with low cirrhosis scores (i.e. less seriously ill) were treated.

There was a wealth of ideas and proposals in ODN engagement plans in 2016/17. It will be important to learn what in practice has been implemented, and how successfully, both in terms of outputs and in terms of impact/outcomes. It would be good to identify those interventions which appear to have most impact in case finding people living with hepatitis C and engaging those people in treatment and care.

There was significant variation in how far advanced ODNs were in assessing patient experience and satisfaction. It will be important for such assessments to continue, and for results to be regularly reviewed and acted on by ODNs as well as fed back to patients. It might be useful for ODNs to compare survey questions and have some core questions in common to support comparability across areas – patient representatives should be central to the development of such questionnaires.

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### Notes

- i NAT 2013 'HIV and Injecting Drug Use'
- ii G Ireland et al 'Prevalence of diagnosed HIV infection among persons with hepatitis C virus infection: England, 2008-2014' HIV Medicine (2018), 19, 708-715
- iii <https://www.england.nhs.uk/wp-content/uploads/2017/08/ccp-statement-retreatment-chronic-hepatitis-c-infection.pdf>
- iv The first ODN merged values for F1 and F2 scores so we have done the same for the other two ODNs to aid comparison
- v The second ODN divided up their patient cohort slightly differently from a simple fibrosis score tabulation—we have approximated cut-off points in relation to fibrosis scores and this gives a sense of the distribution of patients in terms of their morbidity

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