FACILITATORS AND BARRIERS TO HEALTH CARE ACCESS AMONGST PEOPLE USING IMAGE AND PERFORMANCE ENHANCING DRUGS IN WALES

FINDINGS & OUTCOMES REPORT
About Public Health Wales

Public Health Wales exists to protect and improve health and wellbeing and reduce health inequalities for people in Wales. We work locally, nationally and internationally, with our partners and communities.

The Substance Misuse Programme works to address both the current and emerging public health threats in Wales and in line with the overarching strategic objective to ‘reduce health inequalities, and prevent or reduce communicable and non-communicable disease, wider harms and premature death related to drugs and alcohol’.

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About Public Health Institute

The Public Health Institute at Liverpool John Moores University specialises in applied research addressing health issues at all levels from policy development to service delivery. Public Health Institute is committed to a multidisciplinary approach to public health and works in partnership with health services, local authorities, judicial bodies, environmental services and community groups.

Influencing health service design and delivery, as well as health related policy, the Public Health Institute’s research has been at the forefront of the development of multi-agency strategies to promote and protect public health.

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Acknowledgements:
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Suggested citation:
Building on the national surveys of image and performance enhancing drug use undertaken in both 2015 and 2016 (available at: www.ipedinfo.co.uk), a qualitative research project was undertaken in Wales to explore the barriers and facilitators to health care access amongst people using anabolic-androgenic steroids (AAS) and other image and performance enhancing drugs (IPEDs). The aim of this research was to identify low cost (<£5k) or no cost service improvements and interventions to encourage early engagement with health and related services by people using IPEDs in order to reduce health harms, be they physical, psychological and/or social.

This study utilised data and ideas gathered through semi-structured qualitative interviews with individuals using anabolic–androgenic steroids and those providing community-based health and related services that should be accessed by this group and an Evidence Gathering and Synthesis Event which involved a wide range of stakeholders. Ideas for services improvements identified through these activities were then synthesised into a number of recommendations.

Whilst this work was undertaken in Wales, in light of the findings from the previous IPED surveys and extensive engagement with this population across England, Scotland and Wales, the findings and recommendations are considered to be generalizable to the wider UK population using AAS and other image and performance enhancing drugs.

**1.1 Key findings**

Within this study reported durations of AAS use varied from a couple of years to several decades and motivations for use were varied and often changed over time. However, it was often perceived by individuals that their motivating factors were often undervalued or misunderstood by health professionals, with little credit being given to other lifestyle commitments e.g. diet and training.

All participants using AAS had experienced or witnessed harmful side effects linked in part or fully to AAS use, however the majority of participants minimised the health risks. Concerns were raised by all participants groups regarding the availability and accessibility of evidence based information for both people who use AAS and other IPEDs and frontline professionals.

Most participants perceived their AAS use to be problematic in terms of incurring social risk, many felt judged by friends, family, work colleagues, and health care services. This negatively impacted on their willingness to disclose AAS use to health professionals and to seek appropriate healthcare. Facilitators to service engagement included non-judgemental and knowledgeable staff who were willing to acknowledge participants’ own expertise and offer targeted services.

It was widely recognised by all that there was a growing use of online technologies by individuals using AAS as a method in obtaining injecting paraphernalia and accessing metabolic testing. Such services were commonly viewed as more convenient and accessible when compared to traditional methods, and highlighted the importance for wider outreach and engagement services.
1.2 Recommendations

a. Government bodies, academic institutions and health services to provide resources and undertake a review with the aim of developing the evidence base on the use of online technologies (including social media) to facilitate effective health service engagement and e-clinics. This work should include online advice and triage clinics targeted towards young people using AAS currently not engaged with existing services.

b. Public health bodies, community substance misuse leads and commissioners to develop best practice guidance on the implementation of effective assertive outreach services and adaptation of health and social care settings to optimise on-site engagement.

c. In collaboration with registered professional bodies (including; RCGP, RCN, RCPsych, GPhC), public health bodies to develop value-based ‘AAS for healthcare professionals’ training and knowledge sharing opportunities (including e-learning and GP cluster events). Products to be embedded as a core training programmes within NHS Trusts/Health Boards and community health services.

d. Adopting a ‘whole person’ approach, substance misuse commissioning boards to undertake a biennial comprehensive network mapping and gap analysis exercise of local health and social care services accessible to individuals using AAS. The mapping and gap analysis exercise should include:
   • Substance misuse and harm reduction
   • Physical health, mental health and wellbeing
   • Diet, nutrition, exercise and training advice
   • Sports injury
   • Sexual health and wellbeing

   This work should lead to the development of a local/regional service directory for dissemination via outreach services, local health and social care expert AAS fora and establishment of dedicated AAS health and well-being clinic sessions within existing services.

e. Public health bodies and AAS leads to produce the following essential documents:
   • A ‘What to expect’ document developed for distribution across gyms/fitness venues aimed at owners, managers and staff on working with AAS outreach services
   • Collation of all local/regional AAS health and social care directories for inclusion on national websites e.g. IPEDInfo.co.uk
   • A written statement on the implications and importance of AAS disclosure during a medical consultation or treatment

f. Public health bodies in collaboration with UK wide academic institutions to undertake research to establish a robust prevalence estimate of AAS use and evidence of harms associated with use.
2 Introduction

“Evidence suggests there has been a rise in non-prescribed use and injection of image and performance enhancing drugs (IPEDs), particularly anabolic-androgenic steroids (AAS) and associated drugs, in the United Kingdom over recent decades. In particular, the estimated number of 16 to 59 year olds reporting lifetime use of anabolic steroids in the Crime Survey for England and Wales has increased from 194,000 in 2005/06 to 271,000 in 2015/16. The survey is likely to be unreliable for rare events like anabolic steroid use and so it may under-estimate the extent of their use; however, data from needle and syringe programmes also indicate that use of IPEDs is likely to be increasing.

The motivations for using AAS and other associated IPEDs are varied, and these and the other drivers of use have probably changed over time. Among longer established groups of people using AAS and associated drugs, such as bodybuilders and strength athletes, who have been most studied, being “bigger, stronger” is typically the rationale. However, there are a wide range of issues impacting on use and a more complex picture of interrelated factors associated with body image, masculinity, psychological well-being and early influences has emerged.

The use of IPEDs, including AAS, for aesthetic purposes probably represents the most common driver of their use in the UK. Recent work to develop typologies of AAS use has identified four broad types of people using these drugs: the expert, the athlete, the wellbeing, and the YOLO (You Only Live Once) types (Figure 1). Though these groupings are likely to need further refinement, they illustrate the heterogeneity of those using AAS and associated IPEDs.

There are a diverse range of IPEDs that are being used, these include, “fat burners”, tanning agents and a range of hormonal products designed to assist or accelerate physical or physiological changes, as well as AAS. Whilst some of these substances are recognised medical preparations, some are sold as ‘research chemicals’ with little or no clinical testing. These drugs are frequently sourced illicitly. Evidence from testing of seized products shows a significant proportion are counterfeit or home produced, and as such; are of highly variable quality, may contain substances other than those reported on the label, have varying dose strengths, or have a high bacterial load; all of which can contribute to potential serious health risks and harms.

A number of potential health risks have been identified with the use and injection of AAS and other associated IPEDs. Many well established harms of AAS are comparatively minor (e.g. acne), however other harms include more severe physical (e.g. cardiovascular disease, damage to the liver) and psychological (e.g. mood changes, increased aggression) problems. Many IPEDs, including AAS, can be injected, and so their use can lead to health issues that result from poor or unhygienic injection practice, including soft-tissue damage and infections.
Figure 1: A typology of men using anabolic-androgenic steroids and their risk by Christiansen, Vinther & Liokaftos (2016)

Whilst it is clear that there are harms associated with the use of AAS and associated IPEDs (figure 2), the uptake of healthcare and prevention services related to these is often poor.\(^\text{15}\) Data indicates that people who use these drugs will often choose to either wait for symptoms to go away or self-medicate with ‘natural remedies’, over the counter medication, or diverted pharmaceuticals.\(^\text{16, 17}\). For example, findings from the recent national IPED Info survey\(^*\) indicated that more than half that people who use these drugs will often choose to either wait for symptoms to go away or self-medicate with ‘natural remedies’, over the counter medication, or diverted pharmaceuticals.\(^\text{16, 17}\). In part, this reluctance to use healthcare services is probably due to the effects of the substances they use on their bodies. These potential harms could be reduced through regular metabolic testing and prompt health care seeking in response to symptoms of a possible problem. The little available evidence indicates that regular metabolic testing is limited, and typically done privately, and those using IPEDs may not always recognise symptoms or readily access health services in response to these.

People who use AAS and other IPEDs can experience a range of preventable acute and chronic health problems due to the effects of the substances they use on their bodies. These potential harms could be reduced through regular metabolic testing and prompt health care seeking in response to symptoms of a possible problem. The little available evidence indicates that regular metabolic testing is limited, and typically done privately, and those using IPEDs may not always recognise symptoms or readily access health services in response to these.

In addition to the harms associated with the use of AAS and other IPEDs, evidence indicates a range of additional risk behaviours common amongst some of those using these drugs including sexual risk taking (Figure 2), which may result in sexually transmitted infections, psychoactive drug use and high alcohol consumption levels.\(^\text{6}\).

\(^*\) Available at: http://www.ipedinfo.co.uk/resources/downloads/2016%20National%20IPED%20Info%20Survey%20report%20FINAL.pdf
2.2 The study

This report presents the key findings and recommendations from a research study that aimed to evidence the barriers and facilitators to accessing health services among people injecting AAS and other associated IPEDs. The focus of this work was to identify low cost/no cost (that is at a cost between £0 and £5K per annum) service delivery modifications that could improve the availability and acceptability of prevention initiatives and early health care interventions for this group. These interventions should aim to address one or more areas of health, including physical and psychological health and well-being, injecting site infection, injury identification and treatment including use of analgesia and risk of dependency, hepatitis B vaccination and blood borne virus testing.
3 Method & Participants

This study utilised three data collection activities involving people from across Wales.

1. Two sets of semi-structured qualitative interviews explored understandings of the harms associated with using AAS and other associated IPEDs, and the barriers and facilitators to accessing health services, involving:
   a. Individuals using anabolic–androgenic steroids
   b. Individuals providing community-based health and related services that should be accessed by this group.

2. An Evidence Gathering and Synthesis Event which involved a wide range of stakeholders including providers of a range of NHS primary and secondary care services

Recruitment for the two sets of interviews took place in a number of selected local areas across Wales. Though these were pragmatically selected, they were geographically diverse reflecting a mix of urban and more rural settings. Participants in the Evidence Gathering and Synthesis Event were from across Wales. This study was approved by LJMU Research Ethics Committee.

3.1 Interviews with people using anabolic–androgenic steroids (AAS)

The semi-structured interviews with men aged 18 years or over who were using AAS were conducted face-to-face. Participants were recruited from three regions in Wales; North East Wales, South and South East Wales Valleys, and Cardiff. The recruitment approach aimed to include participants who were using AAS for: ‘occupational’ reasons, those engaged in amateur competitive sport, and those whose use was for aesthetic purposes.

Participants were recruited in each area through individuals working in community settings and in specialist gyms who come into contact with people who are using AAS. These individuals acted as ‘gatekeepers’ introducing possible participants to a researcher and/or facilitated the study researcher’s access to recruitment settings.

Interviews were undertaken between autumn of 2017 and summer of 2018, and were usually audio recorded, where the participant didn’t want to be recorded detailed field-notes were made. All participants provided written consent before being interviewed, and could opt out of the study at any point.

The interviews were undertaken by trained researchers in a private safe space, convenient for the interviewee and lasted between 30 and 75 minutes. An agreed topic guide was followed during the interviews that explored their use AAS and other IPEDs, their knowledge and experience of harms related to use of these and health service engagement.

3.1.1 The participants

A total of 17 participants were recruited from three regions in Wales; North East Wales (5), South and South East Wales Valleys and Cardiff (12). There ages ranged from 20 years to 53 years old. The participants report durations of AAS use that varied from a couple of years to several decades.

All of the participants were men, and they included people who were using AAS for ‘occupational’ reasons, those engaged in amateur competitive sport, and those whose use of anabolic–androgenic steroids was for aesthetic purposes. Of the interviews, 13 were audio recorded and detailed field-notes were made for the four who declined to be recorded.
3.2 Interviews with those providing services

Semi-structured interviews were undertaken with invited individuals who were employed in, or led, community-based health, social care or related services that were being, or could have been, accessed by people who use AAS. These interviews lasted between 30 and 45 minutes, and were conducted either face-to-face or, when this was not practical, by telephone.

A list of relevant service providers was accessed through Public Health Wales and service directories. Those identified were initially emailed information about the study. Agreement to participate and the arrangements for interview was then established via telephone. All participants provided written consent before their interview, and were able to opt out of the study at any point.

The interviews were conducted by a trained researcher in a private and safe environment, usually at the person’s place of work. Semi-structured interviews were then completed following an agreed topic guide which explored: their role in current service provision, their knowledge of the use of AAS and other IPEDs, and their understandings of possible barriers and facilitators to service access.

The interviews were digitally recorded, and the researcher took additional field notes as needed to support the interview process. The recordings themselves were used in the analyses, alongside interview notes.

3.2.1 The participants

Interviews were completed with eight service providers during the autumn of 2017 and the winter of 2018. Participants worked in a range of settings including, needle and syringe programmes, drug use related outreach, community pharmacists, and professionals involved in the provision of community based sport and fitness related healthcare. All were currently working in roles that involved direct contact with people using IPEDs, and had been in their current role for at least several years.

3.3 Evidence Gathering & Synthesis Event

The Evidence Gathering and Synthesis Event for the study was held in Cardiff on the 7th November 2018. It brought together a range of people including those from healthcare, public health, and the drug use fields, with people who had experience of using AAS and gym owners. Its overall aim was to explore options for service delivery developments that could improve the uptake of health services by those using AAS and other IPEDs for acute health issues; the prevention of health problems; and providing harm reduction interventions. The focus was on practical and low cost ideas for service delivery developments.

The day operated under the ‘Chatham House Rule’ to encourage frank and open discussion. Participates didn’t have name badges and they were not provided with a list of fellow participants.

The Evidence Gathering Event was structured on the COM-B behaviour change model. The first part of the day involved structured mixed groups discussions to explore issues impacting on service uptake using the following four questions:

**Question 1:** Can you identify, explain and discuss lifestyle factors or behaviours that may influence early engagement amongst IPED users for physical, psychological and social/relationship issues?

**Question 2:** Can you identify, explain and discuss social and environmental factors that may influence early engagement amongst IPED users for physical, psychological and social/relationship issues?
**Question 3:** *Can you identify, explain and discuss policy and practices (of providers) that may influence early engagement amongst IPED users for physical, psychological and social/relationship issues?*

**Question 4:** *Can you identify, explain and discuss access and quality issues within existing health and related services that may influence early engagement amongst IPED users for physical, psychological and social/relationship issues?*

The discussion in each group was led by an experienced facilitator and a scribe took detailed notes, and as needed asked the group to validate the recording of key points. After the groups session all participants came together for an interactive feedback session to allow reflection on the groups’ discussions.

After lunch the key findings from the two sets of interviews undertaken as part of this study (see sections 3.1 and 3.2 above) were then presented and then discussed. Service delivery developments that were generated from both the interviews and during the group work in the morning were then developed by the study team into a set of suggested outline options for service delivery developments and improvements. The participants were then asked to vote on whether they supported each of these using an anonymous interactive smart phone application. The voting choices for each of the suggested options were: ‘Strongly Agree,’ ‘Agree,’ ‘Disagree,’ or ‘Strongly Disagree.’
4 Findings and observations

In this section the conclusions arising from the study findings are presented. A summary of findings from the semi-structured interviews conducted with people using AAS, service providers and the Evidence Gathering and Synthesis Event that underpin these conclusions and the recommendations are also presented within this section.

Findings have been categorised and tabulated into the following core themes:

- Motivations, knowledge and information
- Identity, stigma and relationship with services
- Service delivery, practices and policy

In addition, the preliminary recommendations for service improvements that developed from the interviews and during the Evidence Gathering and Synthesis Event have been summarised in this section.

4.1 Motivations, knowledge and information

Both the observations and evidence related to the first theme Motivations, knowledge and information from qualitative interviews with people using AAS, service providers and the Evidence Gathering and Synthesis Event discussions are detailed in Table 1 (T1).

4.1.1 Motivations for use

In this study a wide range of motivations were reported by the participants using AAS which had contributed to the initiation and continuation of use; these included meeting sporting or body building goals, but also confidence and body image issues. A common theme was that the motivations for using AAS and other IPEDs change throughout someone's life, making categorisation difficult and dependent on other life goals, physical and mental health at the time.

Perceptions amongst service providers about why people used AAS and other IPEDs were often related to the types of clients they had engaged with. Overall the participants felt that the predominant group of people using AAS and other IPEDs were those using these drugs for aesthetic enhancement purposes. Use of these substances for aesthetic enhancement was seen as a reflection of the increasing social pressures related to male body image. These pressures were perceived by services as being widespread in society generally, but also as being important within many social networks and in gym and fitness environments [T1 row 1.1].

4.1.2 Perceived risk and harms

Knowledge and information surrounding both the short and long term effects of AAS use was typically well recognised amongst the interviewed participants using AAS. However, perceptions of safety were often relativized in the context of the use of other substances, participating in other healthy lifestyle behaviours (e.g. weight training and exercise, managed diet), and taking personal responsibility around their use [T1 rows 1.2, 1.3].
Amongst service providers, the accessibility of reliable and appropriate knowledge and information related to the use and effects of AAS and other IPEDs by those using or thinking about use, was another common theme [1.2]. There were concerns that many people using these drugs relied on internet forums, websites, their peers, and their ‘dealers’ for information about what to use and how to use AAS and other IPEDs. Information from these sources, though sometimes robust, is often incomplete, and sometimes inaccurate and misleading. Furthermore, sexual health risks and risk of blood borne viral infection were often underestimated. It was felt making access to reliable, neutral and scientifically based information was seen as an important area for action. Such information is available on a number of websites, though these sites may need some further development to ensure they are up-to-date, engaging and accessible. It was suggested that better signposting of people to these reliable sources of information using a range of means would be useful.

All interviewed participants using AAS had experienced or witnessed harmful effects linked in part or fully to the use of AAS. Whilst the potential impact of such side effects were recognised by most, in some cases impact was trivialised or disregarded [T1 row 1.4]. In the main, the management of side effects varied depending on its perceived nature by the individual. For example, effects perceived as cosmetic in nature (e.g. gynecomastia, acne, testicular atrophy) tended to be self-treated, whereas most felt they would seek medical advice for more serious side-effects that involved major organs [T1 row 1.5]. Discussions between service users and service providers surrounding side-effects often related to cosmetic and acute health effects rather than long term impacts associated with use.

Concerns were raised within all participant groups about the levels of knowledge and understanding of the use of AAS and other IPEDs amongst those delivering services that are, or should be, being used by people using AAS and other IPEDs. There were particular concerns in relation to those staff working in pharmacies providing needle and syringe programmes, due to the high staff turnover and limited time for training, and also amongst primary care providers. It was suggested training should be available through easy to access routes, such as, online courses including refresher training. The training should cover approaches to effective engagement with this group, in addition to providing understandings of the reasons for, and nature of, AAS and other IPED use.

For Table 1 - see overleaf.
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<thead>
<tr>
<th>No.</th>
<th>Theme</th>
<th>Observation</th>
<th>Participant</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>1.1</td>
<td>Motivations for use</td>
<td>Social/societal motivation</td>
<td>Participants using AAS</td>
<td>“Erm, I’d be lying if I said it wasn’t an aesthetic aspect to it, I’d be lying if I said that.” (DA07)</td>
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<td></td>
<td></td>
<td>Perceived risk and harms</td>
<td>Participants using AAS</td>
<td>“Er, well with boxing, I might say it’s to get fit, erm, but more vanity really” (DA08)</td>
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<td>Service Provider</td>
<td>“… it is about body image, it is peer pressure, wanting to look good, want to have better muscles than someone else at the gym…” (GM08)</td>
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<td>Service Provider</td>
<td>“aesthetic reasons [are the most common], it’s the pressure in terms of male body image has definitely I would say has dramatically increased in the last one or two decades, certainly now very much more pressure for men to look a certain way, go to gyms, and engage with at least some element of health and fitness, they are saying that fit is the new rich; I think that is the largest population taking it, to look a certain way”. (GM05)</td>
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<td>1.2</td>
<td>Perceived risk and harms</td>
<td>Perceptions of risk</td>
<td>Participants using AAS</td>
<td>“I think the side effects are potentially over egged. It’s only those using huge doses, over lots of cycles and several years, who tend to suffer.” (DA10)</td>
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<td>Participants using AAS</td>
<td>“From my experience, I have found them to be very safe to be honest. The only thing that is ever in question is source and lab and legitimacy.” (DA07)</td>
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<td>Participants using AAS</td>
<td>“I think as long as you’re not abusing it... I’m blasé about it, injecting steroids, it doesn’t even enter my head, the risks.” (C01)</td>
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<td>Participants using AAS</td>
<td>“I think it can be as safe as anything, to be honest, if it’s used correctly.” (DA02)</td>
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<td>Participants using AAS</td>
<td>“I think it’s done correctly and you’ve got the right sort of advice - it’s safe.” (DA06)</td>
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<td>Evidence gathering event</td>
<td>Sources of information were typically online, and often based on anecdotes, or literature summaries, and from non-official sources. The internet was perceived as the main source of information, with internet searches and forums used to see what others are using. Some people also sourced detail about where and how compounds are made, including quality of production. People are interested in what works, what doesn’t work, interpretation of blood tests, what supplements to take, etc., but quality of information accessed online about these is not assured.</td>
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<td>Service Provider</td>
<td>“Males now more aware of the body shape”. (GM04)</td>
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<td>1.3</td>
<td>Perceived risk and harms</td>
<td>Relativized risk taking</td>
<td>Participants using AAS</td>
<td>“I think it can be used at a safe level, like any drug, like alcohol, like tobacco... I think it’s very safe to be honest, safer than recreational drugs.” (C01)</td>
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<td>1.4</td>
<td>Perceived risk and harms</td>
<td>Minimising the impact</td>
<td>Participants using AAS</td>
<td>“Didn’t have any damaging effects.” (C03) Subsequently he went on to describe being hospitalised for a cardiac event attributed at least in part to his use of AAS. This prompted him to give up taking AAS after two decades of use. (DA07)</td>
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<tr>
<td>1.5</td>
<td>Perceived risk and harms</td>
<td>Considered risk taking</td>
<td>Participants using AAS</td>
<td>“In regard to, as you say, things like my liver, my kidneys, things like that, then, y’know, definitely, definitely, go to the doctors. With things like as I did with gynecomastia and things like that, I’d try and treat them myself. The more visual stuff, I try and do myself.” (DA08)</td>
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<td>Participants using AAS</td>
<td>“If I was having heart issues for example, or I was having some sort of kidney issues, then yeah, no, I would go to the GP ‘cos at the end of the day, while I wouldn’t be happy because I know what their response would be (‘Well, it’s self-inflicted’) they still have a duty of care to treat me... at the end of the day my health is ultimately sort of a bit more important than my pride.” (DA07)</td>
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<td>Participants using AAS</td>
<td>“I’m not concerned about any side effects really, none of my peers have experienced anything and I know guys in their 50’s and 60’s who were using back in the 1980’s. I suppose from the ones you hear about anything to do with my heart concerns me. I’m doing this to be at my best and not to mess my heart up. But I’m confident in what I’m doing. I haven’t had any blood pressure or other tests. I can’t remember that last time I went to a GP to be fair.” (DA11)</td>
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<td>Service Provider</td>
<td>“[some] people will say I bought them off the internet... [They will say] ‘yeah I don’t really know what I am taking’... as long as they can get the end results, it doesn’t put them off at all” (GM03)</td>
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<td>Service Provider</td>
<td>“The benefits of having a more muscular body, and being better than someone in the gym, is worth some of the side-effects which they possibly don’t believe will happen to them” (GM08)</td>
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Table 1 Continued overleaf.
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<td>Service Provider</td>
<td>“...their concerns are more cosmetic, size of testicles, gynecomastia, acne, those sort of things.” (GM01)</td>
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<tr>
<td>Service Provider</td>
<td>“I think, they know about the risks, but they choose not to, [pause] think about the long term consequences, because it easier not to think about it” (GM03)</td>
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<td>Service Provider</td>
<td>“There is a large belief – and this is really prevalent in the community – that, yes I have taken steroids and there are some risks, but I don’t smoke, I don’t drink, and I exercise every-day, unlike my peers, so therefore I am healthier.” (GM05)</td>
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<td>Evidence gathering event</td>
<td>Many people who use anabolic–androgenic steroids and other IPEDs were perceived by the participants to be aware that there are potential harms, but also to think that they ‘won’t happen to me’. However, the participants perceived that if someone had a major or significant health effect it would make them seek healthcare, but minor ones would probably not.</td>
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<tr>
<td>Evidence gathering event</td>
<td>Willingness to self-medicate problems was felt to be common amongst people using anabolic–androgenic steroids and other IPEDs as many already try to self-manage the common side-effects of use.</td>
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</table>
4.2 Identity, stigma, and service engagement

In this study a wide range of motivations were reported by the participants using AAS which had contributed to the initiation and continuation of use; these included meeting sporting or body building goals, but also confidence and body image issues. A common theme was that the motivations for using AAS and other IPEDs change throughout someone's life, making categorisation difficult and dependent on other life goals, physical and mental health at the time.

The observations and evidence related to the second theme Identity, stigma and service engagement from qualitative interviews with participants using AAS, service providers and Evidence Gathering and Synthesis Event discussions are summarised in Table 2 (T2).

It was clear from both the interviews with people using AAS and those delivering services, as well as from the evidence gathering event, that issues related to stigma, particularly embarrassment, about the use of AAS and other IPEDs was an important issue for people using these drugs [T2 rows 2.1, 2.3]. People using AAS and other IPEDs were concerned about disclosing their use of these drugs, this was often related to being concerned about people judging them and being stigmatised because of their use of these drugs. A key consequence of this was a reluctance to engage with services, particularly if these services, or some service staff, were felt to be unknowledgeable or perceived as potentially being judgemental.

Further exploration of the embarrassment experienced by participants using AAS, observed that such feelings tended to manifest themselves during specific points within their AAS using career. In most cases, this was at the point of needing to seek health care advice due to realised health and wellbeing concerns linked to their AAS use. Such individuals described themselves as educated and knowledgeable around potential side effects and yet had made a confident decision to use. However, where they had found themselves in a situation where their use had resulted in them suffering from adverse effects it was at this point participants said they felt/would feel embarrassed [T2 row 2.3].

The findings indicate that service engagement strategies for this group will probably be most effective if they focus on ensuring staff have an understanding of the reasons and drivers for the use of AAS and other IPEDs [T2 row 2.2]. Individuals interviewed who were using AAS claimed that they often felt that their motivations for use were misunderstood, seen as a way of “cutting corners”, and little acknowledgment was placed on the diet and training regimes that accompany use. It was felt that staff who have some understanding of the reasons as to why people use these drugs will offer a more empathetic, non-judgemental and understanding service.

For Table 2 - see overleaf.
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<th>Participant</th>
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<td>2.1</td>
<td>Identity management and relationship with services</td>
<td>Social risk taking</td>
<td>Participants using AAS</td>
<td>&quot;I run a business, so if somebody seen me in there... you get classed as a drug dealer.&quot; (CO3)</td>
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<td>Many of the participants using AAS perceived their use to be problematic, if not for their health, then in terms of incurring social risk. Such individuals felt judged – by friends, family, work colleagues, pharmacists, GPs, and hospital staff. This impacted on their willingness to disclose AAS use to health professionals or to seek treatment for health problems (either AAS or non-anabolic–androgenic steroid related).</td>
<td>Participants using AAS</td>
<td>&quot;I know steroids are frowned upon and they're not exactly legal.&quot; (DA06)</td>
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<td>It was clear that some participants using AAS had experienced social risk taking AAS, such as being regarded as a cheat, a drug dealer, or a drug addict, and there was a widely shared feeling that health professionals disapproved of AAS and other IPEDs and held people who used them personally culpable for their symptoms.</td>
<td>Participants using AAS</td>
<td>&quot;A lot of people out there disapprove and make it quite clear they disapprove especially with a lot of sports governing bodies... there's a big crack down across every sport at the minute. I think they [people using anabolic–androgenic steroids] don't want people knowing that they're doing it, that they're cheating I guess... they hide it, not only from their GP, but they're probably worried that family, friends and loves ones are going to find out.&quot; (DA06)</td>
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<td>Participants using AAS recounted occasions when they had altered their behaviour to avoid feeling judged. And a number of participants felt particularly stigmatised by health professionals.</td>
<td>Participants using AAS</td>
<td>&quot;I think there's quite a stigma attached to steroid users. I know people who've been to healthcare professionals, been to their doctor, been to A&amp;E, and they feel ostracised, where for abusers like heroin addicts, are treated where the addiction is considered an illness. Steroid users... I think are treated like it's self-inflicted, like they've brought it on themselves and they've only got themselves to blame. I think people do look down on steroid users.&quot; (DA01)</td>
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<td>This contrasts strongly with other social environments where AAS and other IPED use is accepted and where the expertise to use them to make 'gains' is respected. As one respondent explained, he could walk into any gym in the world and &quot;It's like being in the Masons.&quot;</td>
<td>Participants using AAS</td>
<td>&quot;I'm not telling my doctor I'm on the gear. I think medical people tend to look down on you if you are. It's your fault you're in here [hospital].&quot; (C03)</td>
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<td>&quot;You're not judged by the harm reduction team. Whereas if you go to a chemist, you're just a drug addict... they don't want to know... Going to A&amp;E... they really do frown on the fact that you've done it... I think they look at you worse than like the heroin user... Somebody who takes steroids is bothered what somebody thinks ... people who do body building have usually got low self-esteem anyway, that's why they start doing it in the first place.&quot; (C01)</td>
<td>Participants using AAS</td>
<td>&quot;You see, the danger is... it is all underground... I think medical people tend to look down on you if you are [using anabolic–androgenic steroids]. It's your fault you're in here. You know, when I was in hospital I didn't get that fact, but I even said to my consultant: I know I probably brought myself in here. I hold my hands up, y'know, and not many people would say that, but I admitted it.&quot; (C03)</td>
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<tr>
<td>2.2</td>
<td>Identity management and relationship with services</td>
<td>Misunderstood/undervalued motivations: A number of participants using AAS felt that health professionals often misunderstood people's reasons for using AAS and other IPEDs and/or did not credit people who use AAS for expertise in achieving sporting or aesthetic goals.</td>
<td>Participants using AAS</td>
<td>&quot;To be the best I can every day. I want to be the strongest I can, the fittest I can and in the best shape I can.&quot; (DA11)</td>
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<td>Comments made during the service provider interviews supported this belief, where many reported that the people they saw who were using, or thinking about using, AAS and other IPEDs, were doing so because they wanted to get a quicker result. That is, they wanted to improve their bodies’ appearance more quickly or with less effort.</td>
<td>Participants using AAS</td>
<td>&quot;I think it’s basically down to stigma. It’s stigma and a lack of understanding or a lack of knowledge on a GP’s part coz they just think you do it and you wanna be bigger, faster, stronger, as big as you can get and, you know, they don’t take it into account that some people who choose that lifestyle, don’t choose it lightly and they will do it and they will have ultimate commitment to it – they can tell you everything they eat, they track all their macros, everything is calculated, their timings, their stacks, y’know, when they go into PC, they know everything about it and they’ve committed so much time but then they can just get poo-pooed by a doctor going, ‘steroid user, out you go.’&quot; (DA07)</td>
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<td>Participants using AAS</td>
<td>&quot;I think other people’s perceptions of someone who uses performance enhancing drugs is they are, you know, 225 pounds, an arsehole, coz they’ve got such anger problems. I think other people’s perceptions are where the issues lies. I’m not embarrassed - it’s just other people think, they expect you to be like some rage monster and that you’re going to be huge.&quot; (DA07)</td>
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<td>Service Provider</td>
<td>&quot;because I think we are nation of quick fix, we want everything now, want it today” (GM03)</td>
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<td>Service Provider</td>
<td>&quot;People wanting to cut corners&quot; (GM04)</td>
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<td>Participants using AAS</td>
<td>&quot;A lot of people I train with I know wouldn’t want to go to A&amp;E or wouldn’t want to go to their doctor and they wouldn’t want any record of them using steroids.” (DA01)</td>
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<td>Evidence gathering event</td>
<td>It was noted that some people saw the use of AAS and other IPEDs as a ‘quick fix’ to getting a better body or being fitter.</td>
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<td>2.3</td>
<td>Identity management and relationship with services</td>
<td><strong>Perceived stigma and shame</strong>&lt;br&gt;Perceived negative attitudes of GPs, A&amp;E staff and pharmacists inhibited participants using AAS from disclosing their AAS use or attending services for AAS related symptoms. This stigma/shame even prevented one or two participants seeking treatment for non-AAS related symptoms since they felt that staff would blame all afflictions on their AAS use and wanted to avoid “a lecture”.</td>
<td>Participants using AAS</td>
<td>“I was really embarrassed when I went to the GP, I play rugby and was taking a banned substance. I know it’s not illegal, but people look at it like it is. I didn’t know what the GP was going to say, I felt like a kid going to the headmaster. I think people have that opinion that they are going to be talked at and almost as if they are going to have a row.” (DA09)</td>
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<td>Participants using AAS</td>
<td>“When there’s actually something wrong with me and it’s caused by steroids, that’s when I feel really sort of embarrassed.” (DA08)</td>
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<td>Service Provider</td>
<td>“Stigma is a big one, umm, there is also a bit of sense of denial about it, if don’t get diagnosed with a heart problem, I don’t have a heart problem, as I don’t have symptoms.” (GM05)</td>
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<td>Service Provider</td>
<td>“…if somebody goes to GP with a sore injection site... I think some don’t want to admit that is how their body developed by sort of cheating with AAS…” (GM08)</td>
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<td>Evidence gathering event</td>
<td>People using AAS and other IPEDs reluctance to disclose their use of these drugs to health and related services may be compounded by people feeling embarrassed by any health problems; as these could be seen as self-inflicted, or imply they had used incorrectly or incompetently.</td>
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4.3 Service delivery, practices and policy

The observations and evidence related to the third theme Service delivery, practices and policy taken from qualitative interviews with participants using AAS, service providers and Evidence Gathering and Synthesis Event discussions are detailed in Table 3 (T3).

4.3.1 Barriers and facilitators to service engagement

A range of issues related to service accessibility and acceptability were noted, including service opening times, service locations, and the environments in which services were provided. For many of the participants interviewed who were using AAS, the topic of confidentiality and the fear of their use of AAS and other IPEDs being recorded within medical records and notes was seen as a significant barrier in engaging with healthcare services [T3 row 3.1]. Their concerns ranged from the fear of being judged at a later date to medical records being passed to employers occupational health departments. This has led to a number of approaches being adopted amongst those individuals including; self-treatment of minor side effects, use of online services to access blood testing and injecting paraphernalia [T3 row 3.3].

There were varying opinions on whether co-provision of services for those using AAS and other IPEDs alongside those for people using psychoactive drugs was appropriate [T3 row 3.2]. Provision of stand-alone services with separate infrastructure is likely to be costly, and probably not sustainable where these would be delivering similar interventions to those provided to people using psychoactive drugs, such as, the provision of clean sterile injecting equipment through needle and syringe programmes. However, in relation to more specialist services focused on IPED specific issues, standalone services may be more practical if these were hosted within generic services. The form and practicalities of such services needs further examination, but the recent development of such a service in Newport, Gwent provides a possible model. The development of such service requires further exploration of a range of delivery models, for example, shared care systems with GPs and e-clinics. Such methods could facilitate ease of access to specialist services across Wales, particularly in rural areas.

The resultant problems with engagement was a very common concern raised repeatedly during the study. Participants suggested various approaches that could be used to improve engagement with services; however, the provision of services by informed, empathetic, and non-judgemental staff was seen as being key to improving engagement [T3 row 3.4]. Some participants indicated that service staff were sometimes overly concerned about not having a complete understanding of the nature of the drugs involved and their use; however, in many settings such knowledge is not necessary to engage with this group. For example, in needle and syringe programmes focusing on harm reduction and practical messages related to injection technique could be an effective approach to engagement. In relation to engaging clients about testing for sexually transmitted and blood borne viral infections, discussions focused around sexual risks are probably a more appropriate and effective approach, than discussions related to risk of infection transmission through injecting.

The use of outreach approaches to access people using AAS and other IPEDs, or who might be thinking about using these drugs, in gyms and other fitness venues was felt to be particularly important; however, there are a number of barriers to this, in particular gaining the support of the venue owners [T3 row 3.3]. Such outreach activities may be particularly effective if they involve credible messengers and peers in their delivery.

For Table 3 - see overleaf.
The provision of more generic well-being services – either through outreach or in fixed sites – focusing on health, wellbeing and fitness, particularly if targeted at young people, may have a role preventing use and supporting other approaches to fitness, such as, diet and training, as well as reducing harm among those who go on to use AAS and other IPEDs.

Related to this, there was concern among those providing services about the lack of access to metabolic testing and treatment interventions for those using AAS and other IPEDs, as currently there are no approved treatment interventions [T3 row 3.5]. Concerns about the provision of, and access to, care for mental health issues for those using IPEDs was very common among the participants. Mental health issues may underpin the use of AAS and other IPEDs for some people, and so being able to address these issues is an important aspect of an effective response.

**4.3.2 Policy issues**

From a policy perspective, service providers and evidence gathering event attendees were particularly concerned about the lack of guidance in relation to providing services to those who use IPEDs, and the related lack of clear and well-defined care and referral pathways for them [T3 row 3.7]. It was suggested this needs to be addressed through development of guidelines on appropriate responses to the use of AAS and other IPEDs for health and wellbeing service providers. There was also support for the provision of guidance to the operators of gyms and fitness venues so as to support outreach, harm reduction interventions, and early identification of those who are experiencing problems related to their use of AASs or other IPEDs.
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<tr>
<td>3.1</td>
<td>Barriers to service engagement</td>
<td>Avoiding documentation on medical records</td>
<td>Participants using AAS</td>
<td>“I paid and had [my blood tests] sent off because I didn’t want that going down as a negative on my medical record, same as a lot of people I know because of the stigma involved. They just go through your medical records going, ‘Ah, I see you’ve been taking steroids.’ It’s just the negative stigma and the lack of understanding.” (DA07)</td>
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<td>Participants using AAS</td>
<td>“I wouldn’t want anything written down on any record with my name that I use steroids. There’s so much negativity... I know people who are so frightened to go to a needle exchange in case they get seen... I don’t think people want to risk others knowing outside of the gym fraternity.” (DA01)</td>
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<td>Service Provider</td>
<td>“Absolutely will not talk about it either because using IPEDs that are illegal and fear repercussions of that, and also along with IPEDs they are using other illegal substances, so absolutely won’t talk because of fear it might get out” (GM05)</td>
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<td>Service Provider</td>
<td>“[In relation to using GPs] there is real concern as well about confidentiality and things being on medical records and those sort of things because they a lot of people do have high powered jobs...” (GM01)</td>
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<td>Service Provider</td>
<td>“Fear of it going on their medical records, of being judged.” (GM02)</td>
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<td>Evidence gathering event</td>
<td>Assessments for new clients, including the need to give personal identification data, with many of those using AAS and other IPEDs being very wary about giving out any such information. This was part of wider concern about confidentiality and the lack of privacy. Privacy issues included concerns about being seen in a needle and syringe programme, and about confidentiality when attending primary care being compromised by the number of staff who could access medical records.</td>
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<td>Evidence gathering event</td>
<td>Contacting a primary or secondary healthcare service about a health problem would require disclosure of their use of anabolic-androgenic steroids and other IPEDs, resulting in concerns about the consequences, such as information about their use going on medical records. This was seen by participants as being a particularly important issue where there were occupational reasons for use.</td>
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<td>3.2</td>
<td><strong>Barriers to service engagement</strong></td>
<td><strong>Perceptions surrounding ‘drug use’ and placement of services</strong></td>
<td>Service Provider</td>
<td>“[they] don’t see themselves as drug users” (GM03)</td>
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<td>Service providers noted that those people that they saw who were using AAS and other IPEDs do not see their use of these drugs as being ‘drug use’. They all noted that people using IPEDs saw themselves as being different from people using drugs for their psychoactive effects.</td>
<td>Service Provider</td>
<td>“they view the substance they are using as not in same league as someone using opiates.” (GM07)</td>
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<td>They were also concerned about the appropriateness of generic substance use services, such as needle and syringe programmes, to those using AAS and other IPEDs, particularly as this group often saw themselves as being different to those using psychoactive drugs and did not want to use the same services as them.</td>
<td>Participants using AAS</td>
<td>“I’ve always felt there’s a bit of a negative attitude towards steroid users... I know people who are so frightened to go to a needle exchange in case they get seen, if they came away with ten syringes they would re-use them.” (DA01)</td>
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<td>These attitudes where mirrored during the interviews with the participants using AAS, with many acknowledging it was difficult attending services where they felt they were viewed as a ‘drug user’.</td>
<td>Participants using AAS</td>
<td>“I didn’t know about specialist exchanges. I wouldn’t go anyway as when I go to the Chemist it’s a public premise/service and I could be going there for anything. Going to one of those places [needle exchange] would put me in that type of box, wouldn’t it? By box, I mean drug user.” (DA10)</td>
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<td>Participants using AAS</td>
<td>“I went to a local drug service and spoke to someone in the needle exchange – that was hard as I know it’s a place where junkies go, and the main door looks out onto the main road.” (DA09)</td>
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<td>Participants using AAS</td>
<td>“You know when I used to go into the drug places [needle and syringe programme] to get my needles... there were heroin addicts in there, there were cocaine addicts... I always thought to myself, y’know, I’m not where you are – I’ve got my own mind, I know what I’m doing. It doesn’t take me into another world basically. I’m still in the real world, even though I’m doing that.” (C03)</td>
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<td>Service Provider</td>
<td>“... a lot of AAS users don’t like coming in [to the needle and syringe programme] when there are other users... like heroin users, because they think they haven’t got a problem... they don’t really come in and have a chat, if you know what I mean, literally just come in and ask for what they want and go” (GM08)</td>
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<td>Service Provider</td>
<td>“IPED users don’t like going to NSP... they see themselves as... we are healthy, we are looking after our health, we are health conscious; they [other NSP users] are not” (GM05)</td>
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<td>No.</td>
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| 3.3 | Barriers to service engagement | Accessibility of services and online alternatives  
Many service providers reported concerns about the opening hours of services, such as needle and syringe programmes, as those using AAS and other IPEDs were typically employed. | Service Provider | In relation to accessing needle and syringe programmes: "... they are buying it [needles and syringes] online, and they don't want to have to go into a needle exchange, and they don't want to wait, and they don't want the stigma; as well it quite rare to come across someone who knows a significant amount about them..." (GM01) |
| | | From the interviews with both service providers and participants using AAS it was clear that utilisation of online services for obtaining injecting paraphernalia and undertaking metabolic testing were both common place. Such services were viewed as more convenient and accessible when compared to traditional methods of service delivery. This reflects the issues with acceptability and availability of the needle and syringe programmes where the same equipment can be obtained for free. | Participants using AAS | "I know people who buy all their equipment online... They buy it online for convenience. You know, you could argue, well you could go to a pharmacy. Yeah, I could go to a pharmacy on a Saturday and Sunday when it's full of people. Don't want that. It's bad enough that people will turn around and go 'Uuugh.' Like I said it's such a stigma." (DA07) |
| | | Throughout discussions during the evidence gathering event it was noted that outreach services have had positive outcomes where rapport and a relationship has been made with gym owners and clientele. | Evidence gathering event | "I paid and had [my blood tests] sent off because I didn't want that going down as a negative on my medical record, same as a lot of people I know because of the stigma involved." (DA07) |
| 3.4 | Facilitators to service engagement | Non-judgmental and informed approach  
Amongst the participants using AAS, key facilitators to service engagement included non-judgemental and knowledgeable staff who were willing to engage in dialogue. Furthermore, reversing the climate of disapproval which people who use AAS felt surrounded front line services was the most prominent topic of conversation. | Participants using AAS | "I think a better understanding, education. If a doctor had a better understanding, I think you would get a better uptake. I can walk into any of the gyms... boys will come up to me like and have the most open conversations with me... Out of the blue, that's the conversations that happens in gyms." (DA07) |
| | | Service providers recognised that staff skill set within services could limit effective service provision. However, many of the participants in this context were overly focused on what they perceived to be theirs, and their colleagues, limited knowledge about the drugs being used. Even though for many this should not have impacted on engagement around issues related to safe injection practice, sexual risk, and motivation for use. | Participants using AAS | "If a centre had specific session for steroid users, then you would know who was going to be behind the door and they would be roughly aware of why you were there without you having to start with, 'And it's because I use steroids.' I don't know where you'd out it though as I think people wouldn't want to be seen walking in, maybe on an industrial estate." (DA09) |
| | | | Service Provider | "A lot of it is time, in that when they come in for equipment they just kind of want to be in and out don't want to be hanging... and may be privacy as well... and then from our point view would be confidence to start the conversation, to know that you were saying was right and that you were giving good advice..." (GM06) |
### Table 3 continued.

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<td>3.5</td>
<td>Availability of health checks and metabolic testing</td>
<td>Steroid specific services were a popular suggestion amongst participants using AAS for improving engagement with services. Especially if services provide opportunities for liver and kidney function screening; drug testing service; home visits; and specific advice on safer use and cessation of use. A common perception among service providers and professionals attending the evidence gathering event was that they were unable to offer services that were often required by those using AAS and other IPEDs. These concerns were particularly focused on the lack of access to health checks, ECGs, and metabolic testing, addressing side effects, supporting the cessation of use, and mental health support. It was widely recognised that services offering such interventions saw people travelling great distances to attend sessions. However, effective delivery models required robust governance and systems for interpretation of results and referral pathways. Further clarity would also be needed on how such services are funded, information is recorded, and clinicians/expertise is retained.</td>
<td>Participants using AAS</td>
<td>There were concerns about the impact when people engage with service providers and finding that they are not knowledgeable about the use of AAS and other IPEDs. Particularly, if staff knowledge and practice is focused on people using psychoactive drugs, such as heroin, as this could be off putting.</td>
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<td>Evidence gathering event</td>
<td>Many participants felt that service providers needed to be welcoming, constructive and non-judgmental, and that they also needed to feel confident working with those using AAS and other IPEDs so as be able to effectively engage with them.</td>
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<td></td>
<td>3.5</td>
<td>Facilitators to service engagement</td>
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</table>

3.5 Facilitators to service engagement

*An actual clinic run by a doctor to help people get off steroids, to address their problems. If you’ve got body dysmorphic disorder, provide counselling, provide support. Provide PCT to get off steroids. If you’ve got [gynecomastia] provide treatment or surgery for that, it may well be you need other services but at this stage, I’ve never heard of or never seen any services directed at steroid users to help them... I don’t think just by providing education or giving steroid users information that you’re going to make any difference whatsoever; you’re just going to alienate them. The only thing I could see that would offer any help would be providing testing ... like WEDINOS do testing services for steroids, so users know what they’re taking is safe, it’s sterile, and they are actually taking what they believe they’re taking.” (DA01)

*As I’ve only used a chemist, I’d say you have to keep that service. But from my reading, I think that if people could have bloods they would be able to better decide what steroids to take and at what dose, they would be able to monitor PCT {post cycle therapy} better and make sure it’s working for them.” (DA10)

*I would have liked a lot more information like this when I visited the drug service, so I think the most important thing is a balanced information service, good, bad and ugly, wart and all. Maybe a leaflet to go with the equipment when you pick it up would help, but I’d prefer someone to tell me, so they can answer any questions I have.” (DA012)

*“It would be cool if we could have specialist steroid clinic in the evenings... where we could offer an extra incentive... sports massage or nutritional advice... even if we could have a nurse that could check bloods or whatever” (GM02)
<table>
<thead>
<tr>
<th>No.</th>
<th>Theme</th>
<th>Observation</th>
<th>Participant</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.6</td>
<td>Policy issues</td>
<td><strong>Availability of clinical guidelines</strong>&lt;br&gt;During discussions that took place during the evidence gathering event many highlighted that whilst there is willingness to explore and develop packages of clinical support for individuals using AAS and other IPEDs, the availability of clinical guidelines related to this topic is currently very limited.</td>
<td>Evidence gathering event</td>
<td>Medical professional’s responses may be limited by their knowledge about AAS and other IPEDs. This can be problematic as having basic knowledge is important to delivering an effective response to people using AAS and other IPEDs when they seek help. It was felt by many participants that in addition to improved training, health and social care providers needed some formal guidance on AAS and other IPEDs.</td>
</tr>
<tr>
<td>3.7</td>
<td>Policy issues</td>
<td><strong>Competing organisational agendas</strong>&lt;br&gt;Professionals attending the evidence gathering event recognised competing agendas between organisations which can result in inconsistencies in approach. The disparity between the harm reduction approaches adopted by health services versus the abstinence approach held by sporting bodies was used as an example to illustrate this point.</td>
<td>Evidence gathering event</td>
<td>Some participants felt there was a need for more focus on this issue at higher levels. The lack of a joined up approach elsewhere in the UK was seen as a barrier, as this can result in inconsistent approaches and messages, which can then have negative impacts on overall confidence in service provision. Cross-border patients have reported that the use of AAS and other IPEDs is less in the open in England than it is in Wales. Service provision and quality varies by location, often reflecting differing agendas.</td>
</tr>
</tbody>
</table>
4.4 Suggested recommendations for service improvement

Throughout the course of the interviews with participants using AAS, service providers, and the Evidence Gathering and Synthesis Event a range of recommendations for service improvements were suggested for wider discussion and consideration. These are summarised below.

Education and awareness raising

- Making it easier for those using AAS and other IPEDs to access reliable and accurate information. Information needs to be modern and relevant, appropriately targeted and engaging and available in a range of formats
- Improve staff skill set through engagement skills training specific to working with those who use AAS and other IPEDs, or who are thinking about doing so
- E-learning, particularly for pharmacy counter staff on key issues related to the use of AAS and other IPEDs and engaging with those who use these drugs
- Better training of, and engagement with, primary care staff particularly GPs. If GPs engaged effectively with those using AAS and other IPEDs, then they could provide a route to accessing metabolic testing and psychiatric interventions, as well as responding to concerns about acute and chronic harms.

Development of specialist care services

- Development of clear healthcare guidelines for providing services to those using AAS and other IPEDs
- The provision of more specialist services for those using AAS and other IPEDs was suggested. In particular doctor led specialist clinics for those using these drugs. It was suggested that this could be a virtual specialist GP led clinic with shared care agreements
- To develop awareness of, and improve responses to, the use of AAS and other IPEDs it was suggested that GPs with specialist interest and knowledge meet quarterly within cluster protected education time (CPET) meetings – so that they could receive training from GP to GP.

Development of existing harm reduction services

- Aim to make service offer appear more engaging to those using AAS and other IPEDs. Engagement should be about offering something that those using AAS and other IPEDs want – such as providing advice on diet or fitness, or access to metabolic testing – and using this to draw people into services so that other interventions can also be delivered
- Focusing interactions in generic settings, such as needle and syringe programmes, on injecting, sexual, alcohol and ‘lifestyle’ risks rather than the drug(s) being used
- Making existing services more acceptable and accessible to those using AAS and other IPEDs, this could include changes to opening hours, offer of specialist sessions, or a more careful approach to providing broad based drug services as well as improving outreach.

Developing other professional networks

- Closer working between services, with clear ‘care’ pathways for those using AAS and other IPEDs
- Improving access to mental health support for those using AAS and other IPEDs through a range of routes
- Closer working with Sexual Health Services in relation to testing for sexually transmitted infections and blood borne virus and for access to vaccinations. This should include awareness raising among staff of Sexual Health Services to support them in identifying those using AAS and other IPEDs. This will provide opportunities within these services for referral and advice provision related to use of IPEDs.
Community and peer to peer approaches

- The development of a common document for use by all gyms with ‘dos and don’ts’ for responsible, safer use of supplements, AAS and other IPEDs. With use of this enforced, i.e. gym licenses mandate on displaying harm reduction information
- Increasing engagement of those using AAS and other IPEDs with services through the use of social media and outreach into gyms
- Develop a peer based network to provide information and harm reduction to those using AAS and other IPEDs – as well chosen peers would be seen as credible messengers
- One respondent suggested consideration be given to co-payment for metabolic testing when this was used for physiological monitoring during periods of use. The co-payment would cover only the actual cost of the test advice and interpretation provided by NHS. However, this approach could be problematic in relation to equity of service access.

4.5 Consensus on preliminary recommendations for service improvement and development

The suggestions and ideas for possible service developments and improvements that arose either during the two sets of semi-structured interviews or during the discussions that took place during the morning of the Evidence Gathering and Synthesis Event were collated and compared. These suggestions were condensed and presented to those attending the Evidence Gathering and Synthesis Event for feedback. To explore consensus for each service improvement and development options, the participants used an anonymous online voting app to indicate if they either “Strongly Agreed”, “Agree”, “Disagree”, or “Strongly Disagree” with each option. The number of participants voting on each suggestion varied slightly, with between 25 and 28 valid votes per option. See Figure 3 for voting outcomes for each service improvement and development recommendation.

The proportion indicating agreement (that is voting for either Strongly Agree or Agree) with the development and improvement options ranged from 20% to 100%. There were only two options with less than 60% agreement. There were four options where agreement was between 60% and 70%, and eight with 100% agreement.

The option with least support – with only 20% indicating agreement – was “Co-payment for metabolic testing for monitoring health”. There would seem to be little support for this option, and for taking this idea further at this time.

Eight options in total had 100% agreement, and considering this high level of support these service development and improvement options should therefore be considered for further development and implementation.
Development and wider promotion of awareness raising products in various formats including information leaflets, QR code business cards provided in a range of environments and in online packs; signposting to credible online info.

Practitioners need to focus on wider health and well-being issues including psychological health as intervention, NOT solely on the drugs.

Development of e-learning module on IPEDs for Primary and Secondary Care services including GPs, Pharmacy

Development of General Practitioner to General Practitioner IPED training model within cluster.

Produce short film on how to engage with individuals using IPEDs.

Dedicated needle and syringe programme staff in all needle and syringe programme sites including pharmacy with increased flexible opening hours.

Improved networking and communication between and within service types (all needle and syringe programmes, all IPED health and allied professionals/services etc); development of local forums.

Establish consistent targeted and tailored health and well-being outreach services (including needle and syringe programmes) co-delivered by health care services and peer champions.

Establish an IPED user group to scope and design an interactive app (e.g., cycle and training diaries) to promote engagement.

Development of targeted/specialist services which aims to address wider well-being including: fitness, diet and supplementation - perhaps tie in with reducing obesity and other public health programmes.

The development of a virtual General Practitioner or IPED clinic available online - utilising contemporary digital health approaches.

**Figure 3: Extent of consensus with the service development and improvement recommendations generated: result of voting during Evidence Gathering and Synthesis day**

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development and wider promotion of awareness raising products in various formats including information leaflets, QR code business cards provided in a range of environments and in online packs; signposting to credible online info.</td>
<td></td>
<td></td>
<td>80%</td>
<td>20%</td>
</tr>
<tr>
<td>Practitioners need to focus on wider health and well-being issues including psychological health as intervention, NOT solely on the drugs.</td>
<td></td>
<td></td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>Development of e-learning module on IPEDs for Primary and Secondary Care services including GPs, Pharmacy</td>
<td></td>
<td></td>
<td>20%</td>
<td>80%</td>
</tr>
<tr>
<td>Development of General Practitioner to General Practitioner IPED training model within cluster.</td>
<td></td>
<td></td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Produce short film on how to engage with individuals using IPEDs.</td>
<td></td>
<td></td>
<td>20%</td>
<td>80%</td>
</tr>
<tr>
<td>Dedicated needle and syringe programme staff in all needle and syringe programme sites including pharmacy with increased flexible opening hours.</td>
<td></td>
<td></td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>Improved networking and communication between and within service types (all needle and syringe programmes, all IPED health and allied professionals/services etc); development of local forums.</td>
<td></td>
<td></td>
<td>20%</td>
<td>80%</td>
</tr>
<tr>
<td>Establish consistent targeted and tailored health and well-being outreach services (including needle and syringe programmes) co-delivered by health care services and peer champions.</td>
<td></td>
<td></td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>Establish an IPED user group to scope and design an interactive app (e.g., cycle and training diaries) to promote engagement.</td>
<td></td>
<td></td>
<td>80%</td>
<td>20%</td>
</tr>
<tr>
<td>Development of targeted/specialist services which aims to address wider well-being including: fitness, diet and supplementation - perhaps tie in with reducing obesity and other public health programmes.</td>
<td></td>
<td></td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>The development of a virtual General Practitioner or IPED clinic available online - utilising contemporary digital health approaches.</td>
<td></td>
<td></td>
<td>0%</td>
<td>100%</td>
</tr>
</tbody>
</table>
Increased General Practitioner prescribing of IPED/Hormone Replacement Therapy in response to long term complications associated with IPED use.

Tailoring of bacterial infection and wound care initiatives e.g. ACT (Act - Care - Treat) project to individuals using IPEDs.

Introduction of co-payment system for metabolic testing for monitoring health associated with IPED use.

Increased/routine availability of drug testing services e.g. expansion of WEDINOS to submissions of IPEDs in Wales.

Increase availability of cardiac and wider health care screening (e.g. ECG testing) within health and well-being clinics.

National roll out of specialist IPED Clinics with inclusion of metabolic testing e.g. South Wales IPED Clinic model delivered in Newport (encouraging inclusion of significant others).

Establish a formal evidence briefing on male Hormone Replacement Therapy for health professionals (and associated others).

Formally recognise IPEDs as a substance group linked to addiction/dependency.

Develop and publish written statement in order to clarify consequences of disclosing IPED use to medical practitioner and legal context of possession/insurance.

Increase engagement with gyms and development of initiatives to improve promotion of harm reduction information e.g. mandatory condition of gym licenses to displaying harm reduction information.

Improved engagement within gym settings - development of a common guidance document with “do's and don’ts” for harm reduction and safer use.
The following recommendations draw upon data generated and collated as part of this study. However, they are principally informed by the ideas generated and voted on at the end of the Evidence Gathering and Synthesis Event. The following recommendations are based on those options that had widespread support throughout this project:

a. Government bodies, academic institutions and health services to provide resources and undertake a review with the aim of developing the evidence base on the use of online technologies (including social media) to facilitate effective health service engagement and e-clinics. This work should include online advice and triage clinics targeted towards young people using AAS currently not engaged with existing services

b. Public health bodies, community substance misuse leads and commissioners to develop best practice guidance on the implementation of effective assertive outreach services and adaptation of health and social care settings to optimise on-site engagement

c. In collaboration with registered professional bodies (including; RCGP, RCN, RCPsych, GPhC), public health bodies to develop value-based ‘AAS for healthcare professionals’ training and knowledge sharing opportunities (including e-learning and GP cluster events). Products to be embedded as a core training programmes within NHS Trusts/Health Boards and community health services

d. Adopting a ‘whole person’ approach, substance misuse commissioning boards to undertake a biennial comprehensive network mapping and gap analysis exercise of local health and social care services accessible to individuals using AAS. The mapping and gap analysis exercise should include:
   • Substance misuse and harm reduction
   • Physical health, mental health and wellbeing
   • Diet, nutrition, exercise and training advice
   • Sports injury
   • Sexual health and wellbeing

This work should lead to the development of a local/regional service directory for dissemination via outreach services, local health and social care expert AAS fora and establishment of dedicated AAS health and well-being clinic sessions within existing services

e. Public health bodies and AAS leads to produce the following essential documents:
   • A ‘What to expect’ document developed for distribution across gyms/fitness venues aimed at owners, managers and staff on working with AAS outreach services
   • Collation of all local/regional AAS health and social care directories for inclusion on national websites e.g. IPEDInfo.co.uk
   • A written statement on the implications and importance of AAS disclosure during a medical consultation or treatment

f. Public health bodies in collaboration with UK wide academic institutions to undertake research to establish a robust prevalence estimate of AAS use and evidence of harms associated with use.
Doi: 10.1002/dta.30
Facilitators and Barriers to Health Care Access Amongst people using Image and Performance Enhancing Drugs in Wales

Findings & Outcomes report 2020